



# BERITA HOSPIS

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## IF PALLIATIVE CARE IS THE ANSWER, WHAT IS THE QUESTION?

By Dr Ednin Hamzah, Chief Executive Officer, Hospis Malaysia

2016 marks the 25th year that palliative care was formally introduced in Malaysia. Since then there has been the gradual increase in palliative care services in the country and a recent introduction of a specialist training programme by the Ministry of Health. Palliative care services in hospitals are now available in most state capitals. These services are introduced by the government and community palliative care services, mainly helmed through non-government organisations.

On May 24th, 2014 the World Health Assembly in Geneva passed a landmark resolution<sup>1</sup> in support of palliative care as a component of comprehensive care. This resolution focuses on the four pillars: policy, access to medicine, education and implementation. In many countries, the work is guided by strategic planning and the introduction of standards of care.

If palliative care is so important, what is it for? How many doctors and nurses need to be trained? Where should the palliative care services be located? What medicine needs to be available and how much would they cost?

What are the public views about palliative care and how would they like to be cared for at the end of life? Which diseases should have access to palliative care? An answer is only as relevant to the questions that are posed.

### Palliative Care Needs Assessment

Malaysia



2016

Four out of 10 Malaysians will require palliative care at the end of their lives. This translates to an estimated 56,000 patients each year and this number is growing.

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“There is a large burden for palliative care and most of this lies in patients with non-communicable diseases other than cancer. The current emphasis that only cancer requires palliative care needs to be corrected”

In 2015, Hospis Malaysia decided that in order to ascertain the palliative care needs of the country, it needed to take the initiative. Three questions were posed. What is the estimated burden of illness that requires palliative care in Malaysia? What are the attitudes of Malaysians to palliative care? And finally, an attempt was made to gauge the 'quality or standards' of community palliative care services in Malaysia.

In April this year, the results to these studies were published and released by Hospis Malaysia in the 'National Palliative Care Needs Assessment Report 2016', which is readily available at [hospismalaysia.org](http://hospismalaysia.org).

The key findings of the report were that:

The estimated number of Malaysians requiring palliative care is 56,000 yearly. Non-communicable diseases are the top causes of death in adults needing palliative care, with cardiovascular diseases (44%) overtaking cancer (33%) as the main cause. Others are chronic obstructive pulmonary diseases (COPD), diabetes mellitus, HIV/AIDS, kidney diseases and certain neurological diseases such as Parkinson's and Alzheimer's.

However, we were able to estimate that only 8% of the country's palliative care needs are being met. The level of care current healthcare personnel are able to provide is not adequate to deal with the predicted need.

Through a public awareness survey, the public is concerned about end of life issues and more than half the population (53%) lives with someone with a chronic disease. Yet, most do not know what services are available or the type of care they might expect at the end of life. Most would like their care to be in the community (53%) and 61% would prefer to die at home. When given some information about how palliative care can help, 99% agree that palliative care

is important and should be available to everyone in need. They also think that talking about end of life care preferences is important (66%), however, many do not, for fear of upsetting others (89%).

The Needs Assessment raises key questions for both healthcare planners and the government in addressing the burden of care.

There is a large burden for palliative care and most of this lies in patients with non-communicable diseases other than cancer. The current emphasis that only cancer requires palliative care needs to be corrected (see page 4).

The public are supportive of palliative care (90% of those surveyed), and want their care to be in the community. However, services available in the community are uneven.

At present anyone may set up a palliative care service and there are no minimum standards of care to protect vulnerable patients. In dealing with end of life care and dying, people do want to talk about it but are afraid and do not know how to. Public education campaigns may be helpful.

Finally, a National Strategic Plan based on the World Health Assembly resolution that is accessible to the public would be useful. Quality indicators, specifications for key processes and standards of care should be made public and serve as an encouragement to the overall rise in the standards of care in Malaysia. The Quality of Death Study 2015 led by the Economist Intelligence Unit ranked Malaysia 38th out of 80 countries. We surely can do better. ■

<sup>1</sup> Strengthening of palliative care as a component of comprehensive care throughout the life course [http://apps.who.int/gb/ebwha/pdf\\_files/WHA67/A67\\_R19-en.pdf](http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf)

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#### PALLIATIVE CARE MALAYSIA an initiative by Hospis Malaysia

Website: [palliativecare.my](http://palliativecare.my)  
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## CLINICAL TRIALS – WHAT ARE THEY AND WHY DO WE NEED THEM?

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



Clinical trials are research studies which test whether particular treatments are safe and how well they work. They are designed to answer questions such as: Does a treatment work? Does it work better than other treatments? Does it have any side effects? Clinical trials aim to improve health and quality of life for patients.

There are many different types of clinical trials. Many may have heard of clinical trials of new drug treatments, especially in the field of cancer. However, not all clinical trials are drug trials. Some clinical trials are used to find out how best to provide psychological support and interventions to improve symptom control. Some are aimed at improving support and information for patients. Others may look at the impact a treatment has on patients.

Each clinical trial has its own requirements that a person must meet to take part. One should bear in mind that taking part in any clinical trials should always be voluntary and you have the right to leave the trial at any time and for any reasons. The level of medical care you get should not be affected by your decision.

In making treatment decisions, doctors usually use their medical knowledge, clinical experience, up to date evidence published in medical journals, peer discussions and by what they have learnt at conferences. Hence, without clinical trials, there is a risk that patients may be given treatments which do not work and which may even be harmful.

The following are two examples of clinical trials relevant to palliative care:

1. A landmark study by Dr. Jennifer S. Temel showed that introduction of palliative care early after a diagnosis of metastatic non-small cell lung cancer, along with cancer therapy, not only improved patients' quality of life, but it also appeared to prolong survival. (1) This study has helped to raise interest in integrating palliative care into standard cancer care to improve patients' symptoms from their cancer and its treatment. One does not need to wait until a patient reaches his or her final days or hours before introducing palliative care.<sup>1</sup>
2. In a recent Cochrane review involving 62 clinical trials with 4,241 participants, oral morphine is still found to be an effective analgesic for cancer pain. More than 9 in 10 participants had pain that reduced from moderate or severe to no worse than mild when taking morphine. Only about 1 in 20 participants stopped taking morphine because of side effects. A wide dose range of morphine was used in the studies, ranging from 25mg to 2000mg with an average of between 100mg and 250mg. There is qualitative evidence that the efficacy of oral morphine is comparable to other available opioids.<sup>2</sup>

This review goes to show that morphine is still a good choice for cancer pain. ■

- 1 Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Eng J Med* 2010;363:733-42.
- 2 Wiffen PJ, Wee B, Moore RA. Oral morphine for cancer pain. *Cochrane Database of Systematic Reviews* 2016, Issue 4. Art. No.: CD003868. DOI:10.1002/14651858.CD003868.pub4

## WHAT ABOUT ME?

by Dr Ednin Hamzah, Chief Executive Officer, Hospis Malaysia



*There is an increasing body of evidence for the benefit of palliative care treatment for patients with various organ failures, motor neurone disease and Alzheimer's disease*

In a medical ward, Mat, a 59 year old man with advanced lung cancer sits up in his bed. He has just had a course of radiotherapy for his cancer and is feeling some pain in his chest as well as feeling breathless. On Mat's left is a 64 year old man with Chronic Obstructive Pulmonary Disease (COPD), a condition he has had for many years and which is gradually getting worse. He is breathless with very minimal effort and his regular medication is not working as well as it used to. To Mat's right, is a 47 year old man who is in hospital for the fourth time this year because of frequent shortness of breath and chest pains. Five years ago, he was diagnosed to have heart failure and is struggling with the symptoms. During the ward round, the doctor in charge spoke to all three of them about their illness and made some suggestions.

The next day, a palliative care physician came to the ward and spoke to Mat, the patient with lung cancer. Mat was asked how the cancer was affecting him, what symptoms were most troubling and what were the most important things that could make his life better. He was asked what he had been told, what he understood about his illness and where he wanted to be cared for. Options for care were discussed and a plan agreed, together with Mat's own doctor.

With a few changes in his medication, Mat felt less breathless and pain was now hardly a problem. He was happy and plans were made for him to go home. A community palliative care service was contacted and

Mat would continue to be supported by a community team that included professional nurses and doctors, equipped with medications and available for emergency support.

After Mat left the ward, the other two patients looked at each other and asked their physician about palliative care. They said that all of them had problems with breathing and wondered whether palliative care might also be useful for them. 'What about me?' they asked their doctor...

Although much of the early emphasis of palliative care was for cancer patients, palliative care is appropriate for many other illnesses. As palliative care focuses on the symptoms that are associated with life threatening illness and works well in patients where their primary physician continues to provide disease modifying treatment, more and more such patients could benefit from palliative care.

There is an increasing body of evidence for the benefit of palliative care treatment for patients with HIV / AIDS, various organ failures, motor neurone disease and Alzheimer's disease. In some hospitals in other countries, there are specific palliative care services for such diseases.

Both the [World Health Organisation's Global Atlas of Palliative Care at the End of Life 2014](http://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf)<sup>1</sup> and [Hospis Malaysia Palliative Care Needs Assessment 2016](https://hospismalaysia.org/events/special-news/349-needs-assessment-2016)<sup>2</sup> illustrate the scope of illnesses that can benefit from palliative care.

However, in Malaysia, despite this, very few patients with diseases other than cancer are referred for palliative care. Many palliative care services themselves are also hesitant to accept such patients into their care. Improving the standards and competency of palliative care services should improve access to its care.

Palliative Care should never be a 'luxury' option for cancer patients. ■

*Article originally appeared in The Malay Mail Online, June 2016.*

- 1 World Health Organisation's Global Atlas of Palliative Care at the End of Life 2014 - [http://www.who.int/nmh/Global\\_Atlas\\_of\\_Palliative\\_Care.pdf](http://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf)
- 2 Hospis Malaysia Palliative Care Needs Assessment 2016 - <https://hospismalaysia.org/events/special-news/349-needs-assessment-2016>





Hospis Malaysia is grateful for the continuous support it receives from the individuals and corporations that support us through the years. We truly believe that these organisations and individuals recognise the important role Hospis Malaysia performs in the community and for that we are grateful. Thank you for including us in your charitable giving's!

#### MARCH

**1 BOOK LAUNCH: 'THE MALAYSIA THAT COULD BE'**

#### APRIL

**2 CHARITY & NECK TIE ART EXHIBITION 2016** – Long-time supporter of HM, artist Philip Wong

**3 NATIONAL PALLIATIVE CARE AWARENESS WEEK** (See page 6) - Thank you to the Sunway Group/ Sunway Pyramid as the venue sponsor

#### MAY

**4 ARTLIVE 2016 BY GARDEN INTERNATIONAL SCHOOL (GIS)**

**5 WESLEY METHODIST SCHOOL INTERACT CLUB** - Thank you for the support for the third consecutive year!

**6 UCSI's 30th ANNIVERSARY: FREEDOM RUN & FAMILY CARNIVAL**

**7 ABWM & DEBENHAMS': SPRING/ SUMMER 2016 FASHION SHOW LAUNCH** – Thank you to The Association of British Women (ABWM) for the repeated support!

#### JUNE

**8 WATSONS 'PROJEK SUMBANGAN HARI RAYA'** - thank you for the support for the second consecutive year.

**9 BOOK LAUNCH: 'THE SCIENCE OF GETTING RICH DECODED'** – Thank you, ClickEvents!

**10 TAN BOON MING SDN BHD: MID-CLEARANCE SALE**

..and thank you to the many individuals and corporate donors who continue to support us with your donations!

## THANK YOU FOR THAT FINAL CHAPTER

### WORKING TOGETHER AS FAMILY

As with most families in similar situations, my Mom, brother, two sisters and I had to wrestle with the best ways possible to deal with my Dad's condition. We were terrified that we might make the wrong choices, respond in the wrong way or might not react fast enough to his needs; particularly during the daytime when we were all away at work. What we learnt is that there is no right or wrong approach in such situations; and the family as a whole needs to come together to figure out what is possible and acceptable to them.

### AN ADDED LAYER OF SUPPORT

Our worst fear is suffering, pain and death. How do we know if Dad is suffering from pain or discomfort? My Dad experienced various distressing symptoms such as inability to swallow and eat, chest infections and breathing difficulties that troubled him greatly at a physical and emotional level. More so, he had been a fiercely independent and disciplined person all his life. He detested bitterly the loss of control. All we want to do is to take away his suffering.

Hospis Malaysia enabled us to care for Dad at home, in familiar surroundings. The clinical team helped manage Dad's distress. Prior to that, we needed to rush to the hospital every time Dad was in pain or symptoms from his illness flared up. Having Hospis Malaysia's clinical team visit us at our home and supplement the hospital attention greatly helped us on many occasions; it was just not possible to bring my Dad to the hospital without further distressing him.

### NAVIGATING THE HEALTHCARE SYSTEM

Not being familiar with medical terms and the healthcare system, at various points of my Dad's illness, we simply did not know who to turn to and what to do. In these situations, the Hospis Malaysia team helped us to navigate the healthcare system, linking the dots and pointing us to the right direction. There were a number of occasions, when my Dad needed immediate attention; Hospis Malaysia wrote referrals for us.

### EMOTIONAL AND PSYCHOSOCIAL WELL-BEING FOR THE PATIENT AND FAMILY

As much as possible, we tried to maintain a semblance of normalcy; and not let Dad's illness take that away. For example, every weekend, we make it a point to go for morning walks at Lake Gardens.

Mom was tending to Dad's various needs. It was physically and mentally exhausting for her. Apart from thinking about my Dad's needs, in parallel, we also

needed to consider my Mom's ability to cope; that her physical and medical condition was not compromised. Nurse Nadiah and her colleagues at Hospis Malaysia offered a compassionate, listening ear; something that my Mom greatly appreciated. She always looked forward to their visits. Just by being there and listening without judgement helped ease some of mom's emotional burden and stress.

### THE DYING PROCESS

The day my Dad passed, I had this dread coming all over me and immediately called Hospis Malaysia. Nurse Nadiah came two hours later. She checked Dad's vital signs and it became clear to us, although unspoken, that the end was near. At a certain point that afternoon, I asked Nurse Nadiah what will happen next. She explained calmly, 'it looks like the end is near'.

Nurse Nadiah described the physical changes associated with the dying process. Cooling of the hands, arms, feet and legs as blood circulation diminishes, drowsiness and loss of consciousness, reduced intake of water and food, loosening of the muscles, changes in breathing patterns (gurgling sound). She also prepared doses of morphine to ease my Dad's comfort; and taught us how to administer this. We stayed by Dad's side for the rest of the time and he left us in the early morning the next day. Had we not had Hospis Malaysia's support there in our home, we would not have known that it was Dad's final day; and we would have experienced a lot of unnecessary distress and perhaps regrets, for not knowing what to do to ease his path and be there for him.

To say the past 13 months had been difficult is an understatement. Our solace is that, as a family, with loads of help and support, we have in some ways managed to offer my father the following:

- Some relief from pain and discomfort
- To be at peace with his past and things he could not let go
- Reassured him that he lived a fruitful meaningful life
- Showered him with lots of love
- We honoured his wish of dying at home

To the entire palliative care team at Hospis Malaysia, thank you for helping my Dad craft a graceful and dignified final chapter of his life. We are eternally indebted. I know my Dad felt the same way too. Before Nurse Nadiah left our house that fateful day, Dad managed to open his eyes with great difficulty and he patted her on her head - his way of saying thank you for caring. ■

## THANK YOU FOR THAT FINAL CHAPTER

By Siew Yoong Chin, palliative care advocate, daughter of the late Mr Yew Kong Ching

My Dad passed away recently, after battling 13 months with Oral Cancer. Malignant Melanoma - the type of oral cancer that my Dad was inflicted with is both Chemo and Radiation resistant. He underwent surgery to remove the tumour from his upper palate and left cheek. The surgery left him unable to eat, swallow or talk.

He returned home after two months of hospitalisation. Our hope at that point was that with consistent speech therapy, patience and lots of encouragement and prayers, my Dad would heal and regain normal function and activity. However, this was not meant to be. His tumour returned barely two months after the surgery, and this time, cure was no longer an option.





# LAUNCHES NATION’S FIRST ‘PALLIATIVE CARE AWARENESS WEEK’

By Rini Vella, Advocacy & Media, Hospis Malaysia

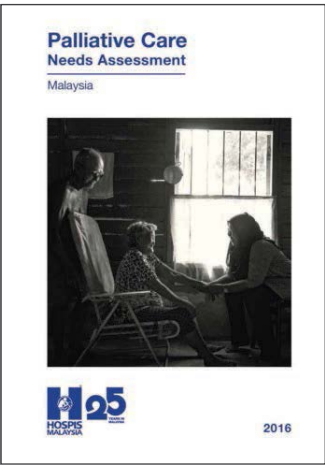
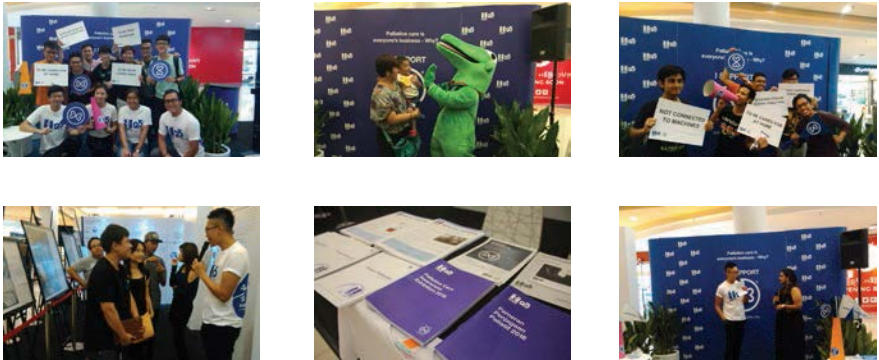
What is palliative care? Why does The World Health Organisation (WHO) consider it a 'basic human right?' and if it is so, why is the accessibility to and minimum standards of this medical sub-speciality inconsistent across the country? What can we do to change this situation?

To shed some light on this, Hospis Malaysia is at the forefront in raising public awareness on palliative care across the country. This year, in conjunction with its 25th year anniversary, Hospis Malaysia launched the first 'National Palliative Care Awareness Week' themed 'Palliative care is everybody's business – Why?' (20-24th April 2016)

"If you were seriously ill, what's important to you?" asked the eight feet high chalkboard demanding passer-by's attention. "Asking such questions could be very helpful to get you to start thinking about the type of care and quality of life you would want for yourself and also to identify what you may not want. It also means talking about this with those close to us. Sometimes, even though we think we know what someone else thinks and believes, we really do not know until we ask", says Dr Sylvia McCarthy, Medical Director of Hospis Malaysia.

"This was why we encouraged partakers to take a photo of themselves with their answers and share it on social media or with their family and friends", explains Dr McCarthy.

"Understandably, these questions may sound difficult to discuss now, when the time for decisions is still in the future. However, studies show that they are harder to discuss when someone is seriously ill, emotions are high, and decisions must be made quickly" Dr McCarthy expresses. The majority of partakers reflected the desire to be with family and close friends, to be cared for at home and to be free from pain and suffering as important to them if they were seriously ill, which echoes the results of the Palliative Care Needs Assessment Report.



# RELEASES NATIONAL 'PALLIATIVE CARE NEEDS ASSESSMENT' REPORT

April 2016 – This year we channelled our research efforts towards addressing a gap of publicly available information. This report attempts to estimate the need for palliative care in the country using a WHO\* framework. Key findings of the study were shared with the public through public awareness exhibitions and the media (see page 1).

\*World Health Organisation

This year, Hospis Malaysia hosted a series of events and initiatives underlining how far we have come in the past 25 years.

# HOSPIS MALAYSIA'S 25TH ANNIVERSARY GALA DINNER



Save the date! On 14 October 2016, come celebrate our 25th year anniversary with us! Witness our impact in the community over the years and how your support has helped us along the way. Let us share with you where our organisation is heading and ways you can continue to support us. Visit [hospismalaysia.org](http://hospismalaysia.org) for more information.

# FUNDRAISING ACTIVITIES



Hospis Malaysia's 15th annual Charity Treasure Hunt (see pg. 8)



Standard Chartered KL Marathon 2016 (SCKLM)

# IN THE MEDIA



# 'PALLIATIVE CARE AWARENESS EXHIBITION' CONTINUES AT BSC



Hospis Malaysia's palliative awareness efforts for 2016 continued at Bangsar Shopping Centre (BSC) from 13-17th July.

A feature of this year's awareness campaign involved a photo exhibition by award-winning photographer, SC Shekar who documented Hospis Malaysia's clinical team together with the patients and families under their care.

The collection of photos was aimed at imprinting a message - though these patients and caregivers were faced with the burden of a life-limiting illness, their quality of life can be improved if they were well-supported in their own home, their pain and other symptoms managed and their dignity preserved.





## EVENTS

### A-HUNTING WE WILL GO!

By Wendy Loo, Advocacy and Fundraising , Hospis Malaysia

**14th May 2016** – Hospis Malaysia’s Annual Charity Treasure Hunt is one of Hospis Malaysia’s oldest fundraising traditions. An event that challenges hunters while taking them on a ‘cuti-cuti Malaysia’, this year’s treasure hunters were set on a trail that led to Malacca, one of the two UNESCO World Heritage Sites in Malaysia.

The teams, including a large contingent from Kelab Sosial Sunway, Sunway Resort Hotel & Spa, and Sunway Medical Centre, started out from Bangsar Village II (Flag-Off Venue Sponsor) after a hearty breakfast sponsored and hosted at Chawan Café. Ranging from long-time supporters to first-timers, the hunters cracked their heads through cryptic clues and mind boggling word play to their final destination at Hotel Equatorial Melaka.

Upon arrival at the final destination, hunters were asked to fix a unique 25-piece jigsaw puzzle – a bonus question that gave a nod to the 25 years of service Hospis Malaysia has provided.

In the evening, as results of the hunt were announced, everyone was rewarded. Team ‘Vettai Sakthi’ was the Grand Prize winner of the 15th Annual Treasure Hunt, after a close and narrow fight with team ‘2 Sneakies and 2 Innocents’.

Hospis Malaysia would like to thank all individual donors and sponsors for their generous contributions, which helped make our 15th Annual Treasure Hunt yet another success!

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### SHARE THE KNOWLEDGE, SHARE THE CARE

Wendy Loo, Advocacy and Fundraising, Hospis Malaysia



Caring for a loved one who is suffering from a life-limiting illness is difficult, particularly when the patient is being cared for at home. Family members have to juggle this added responsibility with their everyday tasks and activities. To make matters worse, most family caregivers are ill-equipped to deal with the symptoms and effects of their loved one’s disease, as well as their basic day-to-day needs. Learning special strategies and basic caregiving skills will allow caregivers to provide assistance to their loved ones in a safe and efficient manner. These tips and skills can also help make patients feel more comfortable, while family caregivers feel more confident, less stressed and better able to cope with and care for their loved one’s condition.

Mindful of these benefits, Hospis Malaysia’s Workshops for Caregivers was started early this year to provide caregivers with the skills, knowledge and resources they need to help care for their loved ones. These sessions, facilitated by Hospis Malaysia’s palliative care nurses, also provide caregivers with some hands-on practice on the topics talked about. Participants are also able to discuss concerns related to their caregiving and potentially find solutions to their caregiving difficulties. These workshops are held monthly, and are offered at no charge.

Among the topics discussed in previous sessions include topics relating to managing pressure sores, stoma and fistulas, lymphoedema, understanding medications as well as issues concerning hydration and nutrition approaching the end of life. These workshops are bilingual, with some workshops presented in English and Malay, and others being presented in English and Mandarin.

“The workshop is interactive, and (what I learnt) can benefit my family member,” said Eleanor Cheah, a family caregiver. Sharon Chen and Patricia Chua, two friends who learnt about the workshops also said that

the workshops had “good advice that can be shared with other people and to help them take care of their loved ones.”

**Please visit [hospismalaysia.org](http://hospismalaysia.org) for the latest Workshop for Caregivers schedule.**

#### SOME TIPS OFFERED DURING THE WORKSHOPS:

1. Administer pain medication 30 minutes before changing a wound dressing to help minimise discomfort and pain
2. When using a drainable pouch, ensure that the outlet is smooth before clipping it shut.
3. Do not massage the limb if there is swelling due to water – you will only make the swelling become worse.
4. Sometimes patients may refuse to eat because the porridge is too bland – add some flavouring by mixing sauce from their favourite food into the porridge.





## WORKSHOP ON ETHICS IN PALLIATIVE CARE

by Rini Vella, Media & Advocacy, Hospis Malaysia



Sumytra Menon discussing consent with workshop participants

Some of the most challenging ethical questions in medicine surround care and decision-making for those faced with life-limiting illnesses. For example, issues related to a patient's autonomy, decision-making, truth-telling and whether to withhold or withdraw treatment. Awareness and appropriate management of such ethical issues set the foundation of quality patient care.

A core belief of palliative care is that patients deserve the best quality of healthcare at all stages of their illness. And studies on palliative care reveal numerous positive outcomes for patients and their families.

In collaboration with the Asia Pacific Hospice Palliative Care Network (APHPCN), Hospis Malaysia's workshop on 'Ethics in Palliative Care' draws on an international panel of specialists in palliative care and experts in medical ethics. The workshop is designed to guide discussions on moral and ethical issues that healthcare professionals may face when caring for patients, particularly those with life-limiting illnesses.

Some key takeaways from the two-day course:

### ON MEDICAL FUTILITY

Determining when to withdraw or withhold treatments deemed medically futile is complex; "Interventions that are unlikely to produce significant benefit for the patient are deemed medically futile. Healthcare providers may feel that by withdrawing treatment, this will be regarded as the abandoning of a patient or as a failure on their part if death occurs. Failure comes not from withdrawing a futile treatment, but from lack of proper communication and poor care" says Assoc. Prof. Ghauri Aggarwal.



(left) Dr Linda Sheahan & Dr Sylvia McCarthy, (right) Dr Ghauri Aggarwal

**Facilitators:** Associate Professor Dr Ghauri Aggarwal, Head of Palliative Care Department, Concord Hospital, Sydney; Dr Linda Sheahan, Honorary Associate with the Centre for Values, Ethics and the Law in Medicine, University of Sydney; Ms Sumytra Menon, Senior Assistant Director at the Centre for Biomedical Ethics, National University of Singapore; Dr Ednin Hamzah, Chief Executive Officer, Hospis Malaysia; Dr Sylvia McCarthy, Medical Director, Hospis Malaysia.

"Good and basic medical care is never futile. The decision to withdraw medical care helps prevent further suffering from inappropriate treatments. We need to stop treatments that prolong the dying phase," Sumytra Menon adds.

### ON PALLIATIVE SEDATION AND OPIOIDS

The relief of suffering is one of palliative medicine's key values. Palliative sedation is an effective, accepted symptom control strategy for patients who suffer with intractable symptoms at the end of life.<sup>1</sup>

Yet, "palliative sedation can sometimes be seen as a shortcut answer to a complex issue" says Assoc. Prof. Ghauri. "It becomes unethical to administer palliative sedation as a shortcut answer, when the family requests for it or due to clinician fatigue, for instance. Discussions that explains why, how and the consequences of what you are doing is essential. Healthcare providers should explore other options first such as proper care and proper assessment before deciding on palliative sedation. Ask, 'whose agenda are we satisfying?'" Assoc. Prof. Ghauri stresses.

<sup>1</sup> Braun TC, Hagen NA, Clark T. Development of a clinical practice guideline for palliative sedation. *J Palliat Med.* 2003;6:345-350. Abstract

## WORKSHOP ON ETHICS IN PALLIATIVE CARE

continued from page 11



"Healthcare providers need to get familiar with the literature on opioids," Dr Linda Sheahan advises. Effective pain relief, especially at the end of life, is a primary ethical obligation based upon the principles of beneficence, non-maleficence, and patient autonomy. Numerous misunderstandings present a barrier to effective pain management. These misconceptions include the idea that opioids are highly addictive, that opioids have a narrow therapeutic range, and that opioids are ineffective by mouth and cause too much nausea. In reality, opioids are the safest and most effective pain medicine for most moderate to severe pain in most patients.<sup>2</sup>

<sup>2</sup> Ethical and practical issues with opioids in life-limiting illness <http://www.ncbi.nlm.nih.gov/pubmed/17256034>

## 2016 UPCOMING EVENTS

### AUGUST

**19th-21st**  
Suffering & Hope  
Workshop

### SEPTEMBER

**23rd -25th**  
Paediatric Palliative  
Care Workshop

### OCTOBER

**14th**  
Hospis Malaysia 25th  
Anniversary Gala  
Dinner

### NOVEMBER

**4th-6th**  
Pain & Symptom  
Management  
Workshop

Please contact us for ticket enquires or to discuss sponsorship opportunities at [pr@hospismalaysia.org](mailto:pr@hospismalaysia.org). For further information, see page 6-7



## HOSPIS MALAYSIA'S ANNUAL CHARITY BAZAAR @ WIP, BSC

**December 4th** - Save the date for Hospis Malaysia's Annual Charity Bazaar! Calling all vendors:

We are seeking an assortment of vendors from nail art, handicrafts and arts, food & drinks, clothes and many more! Corporates and individuals are welcome to sponsor Raffle Draw prizes and packed food and other items towards Hospis Malaysia's stall. Come support Hospis Malaysia and palliative care.

Contact us at [pr@hospismalaysia.org](mailto:pr@hospismalaysia.org) to secure a table or for further enquiries.