

EDITORIAL NOTE

A CHALLENGING YEAR AHEAD

by **Dr Ednin Hamzah**, CEO/Medical Director, HM

A new year beckons although it is preceded by a slew of human tragedies both in Malaysia and the world over. Torrential floods and the tragedies affecting Malaysian linked airlines in these past months bring sadness and grief to many in our communities. The economic situation is also a concern to many this year.

So what does it mean to us within the palliative care arena? What will be the burden of disease that Malaysians will face this year? Are we dreading the possibility that we may have a serious illness this year? And if so, what is the level of capacity and standard of the medical services available in the country?

A report by the Economic Intelligence Unit on Healthcare Outcomes for 2014 saw Malaysia ranked 80 / 166 countries surveyed. In May 2014, Malaysia signed up for the World Health Assembly resolution supporting palliative care. What does this mean for us and for our loved ones if illness affects us in 2015?

In the past year, Hospis Malaysia was referred 2,094 patients, an increase of 20% from 2013. The number of cases at any time under our care is usually between 400 and 450 patients spread across all sections of our society. Many cases are still referred at a very late stage.

Do Malaysians in need of palliative care have access to a standard of palliative care that could make a meaningful difference to their lives? In considering this, several questions should be asked. In the descriptive context, what is the coverage of palliative care in



Malaysia? What is the range of services available? These could include types of illnesses covered, hospital and community based care, government, charity or private facilities. Are there facilities for emergency care, either at home or in hospital?

Patients and families deserve the best care in their moment of distress. What are the competencies of staff and volunteers involved in care giving? What can patients and families expect? Increasingly, with greater awareness for palliative care in the country, we also have patients who have had contact with palliative care services in other countries. Should the standards in Malaysia be similar to that in Singapore, United Kingdom, Australia, and other countries where there may be National Standards in Palliative Care?

Hospis Malaysia is a small organisation with limited resources. We will be 24 years old this year and we have grown significantly over the years. During the first phase of our existence, the focus was to deliver the

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“Palliative care is something that is never important until it is needed”

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Website: www.palliativecare.my
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best care possible for our patients. We then realised that it was not possible for Hospis Malaysia to provide services to the whole of Malaysia. This should be a responsibility of the Ministry of Health. With the Ministry accepting and recognising palliative care in the early 2000's, Hospis Malaysia turned its attention to training and education.

In 1998, Hospis Malaysia started teaching palliative care to medical undergraduates from Universiti Malaya, our training programme now encompasses a busy programme that reaches out to many universities involving both under and post graduate doctors and health care professionals. Furthermore, through our collaboration with the Asia Pacific Hospice Palliative Care Network (APHPCN), palliative care workers from around the region now attend our series of eight yearly workshops.

Not unlike many things (e.g: insurance), palliative care is something that is never important until it is needed. Friday evenings are usually the worst for us when patients are being discharged from hospitals and care at home is needed. But without adequate planning, it is impossible to cater to a large group of patients immediately when there is already a high patient caseload.

“If there are no national standards of care in place, what is the guarantee that the standard of care provided is truly beneficial for patients and their families?”

In May 2014, Malaysia helped sponsor a resolution at the World Health Assembly in support of palliative care. Malaysia has also ratified many other international conventions. With regards to palliative care, the hope is that palliative care will soon be accepted as part of a universal health care plan, where governments have to guarantee access to all citizens regardless of ability to pay. For some countries, this is already implemented.

Some years ago, a patient advocate in a World Health Organisation meeting said 'how can I ask for something that I didn't know exists?'

In Malaysia, many are not aware of what palliative care is and certainly even if they knew, may not be aware of where they could access it. And if there are no national standards of care in place, what is the guarantee that the standard of care provided is truly beneficial for patients and their families?

Last year, Hospis Malaysia launched a campaign to introduce a symbol to embody palliative care. Supported by patients and their families, well-known personalities and the Minister of Health, we hope that our community will soon be able to familiarise themselves with what palliative care is and more importantly, what it is NOT. Do visit, www.palliativecare.my

For many, our New Year resolution may involve adopting life style changes to improve health. For a small number, the diagnosis of a serious illness may come this year. It would be good to be aware of what healthcare services are available. If none are available in your area, do think about supporting either a community initiative or making sure the Ministry of Health is aware of your needs.

Help us help you for 2015.

LOSS OF APPETITE (ANOREXIA) IN ADVANCED CANCER

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

WHEN WILL LOSS OF APPETITE



Patients with advanced cancer often do not feel hungry and hence want less food.

Here are some frequently asked questions about anorexia in patients suffering from advanced cancer:

1. How common is loss of appetite in advanced cancer?

Loss of appetite, also known as anorexia, is common in advanced stages of cancer. It can affect up to 92% of patients with advanced cancer.

2. What causes loss of appetite in advanced cancer?

Cancer treatments, such as chemotherapy and radiotherapy can cause nausea, vomiting, sore mouth, dry mouth, which can decrease a patient's appetite. Pain and depression can also cause loss of appetite. Other causes include infection, unpleasant odours, feeling of fullness due to build-up of fluid in the abdomen, anxiety and breathlessness. Sometimes, the cancer itself causes changes in metabolism as well as loss of appetite.

3. What are the practical tips to improve appetite in advanced cancer?

- Eat small frequent meals throughout the day.
- Try to eat when your appetite is at its best. For many patients this is usually in the morning.

- Eat high-calorie food e.g. full-fat yogurts, evaporated milk/condensed milk in hot drinks, ice cream with desserts, and extra cheese on pasta/pizza
- Eat protein-rich food e.g. fish, chicken, tofu, eggs
- Do not skip carbohydrates e.g. rice, noodles, potatoes, pasta
- Do not fill up on low-energy filling food such as vegetables and fruits
- Drink nutritious fluids e.g. drinks fortified with vitamins and minerals, between meals instead of during meals so they do not fill up the stomach.
- Add a little extra spices/butter/oil/cream to food to improve flavour
- Eat a variety of food in your diet
- Try to eat with your loved ones at the dining table whenever possible

4. Are there any medications to improve appetite?

There are some patients who may benefit from appetite stimulants. Your palliative care nurse or doctor can assess to see if they are suitable for you.

5. Are feeding tubes necessary?

It is often not necessary to have feeding tubes inserted. Loss of appetite and weight loss in advanced cancer will not be reversed with feeding tubes.

HOSPIS MALAYSIA'S CHARITY BAZAAR 2014

7th December 2014 - Despite the scorching weather, more than 500 eager shoppers turned up throughout the day to 'shop for a good cause'. For the second consecutive year, Hospis Malaysia worked in partnership with the Soul Society group to bring about the Hospis Malaysia Charity Bazaar 2014.

"This event hit close to home this year. My colleague's mother in law was in bad shape as her body was ridden with cancer and her prognosis wasn't too good. The whole family did not know how to handle such a situation and turned to Hospis Malaysia; who were professional and empathetic in preparing them for such a situation. The entire family is ever grateful to Hospis Malaysia for all they did in terms of advice, support and just being there in their time of need. Sometimes simply knowing what to expect can help take the fears and anxiety away" remarked Michelle Kwok, Executive Director of the SOUL Society Group.

The Raffle Draw proved to be a hit with 20 very happy guests walking away with fantastic sponsored prizes like a **computer tablet, luxury hotel stays, gourmet French cooking classes, dining vouchers, indulgent food items, electrical appliances and pampering cosmetic and beauty products.**

Thank you to all of you that made it, the generous prize sponsors and to the unique vendors that contributed to our cause and for the continuous support of our friends! #HMBazaar2014.

For the full gallery of photos, please visit us on Facebook: HospisMY



“ The entire family is ever grateful to Hospis Malaysia for all they did in terms of advice, support and just being there in their time of need. Sometimes simply knowing what to expect can help take the fears and anxiety away - remarked Michelle Kwok, Executive Director of the SOUL Society Group. ”



ONE PATIENT'S QUEST TO RAISE AWARENESS FOR PALLIATIVE CARE

30th November 2014 –

Around 300 people, young and old, got together to cycle and raise awareness for palliative care.

The inaugural **'Ride for Palliative Care'** was organised by Hasmah Ibrahim who is receiving palliative care, and her husband Saharuddin Jaafar. The event was sponsored by Yayasan Sime Darby. To kick off the event, the couple jointly pedalled a tandem bicycle leading a group of palliative care advocates who were equally determined to spread awareness on the benefits of receiving palliative care.

Hasmah, despite having a life-limiting illness, was in high spirits and determined to cycle at least the first few kilometres with her husband. Hasmah and her family have been receiving support and care for almost two years with the multidisciplinary palliative care team here at Hospis Malaysia.

"I am thankful for the support from Hospis Malaysia. They manage my pain and symptoms well so I can keep active as best I can."

"We are truly delighted with the number of participants who turned up to support the cause of palliative care," said a beaming Hasmah.

"The aim of organising this event was to not only raise awareness for palliative care but also to raise funds for HM, who will then channel the funds to help others in need. I believe by the number of people here today, we have achieved a little of both. We hope more will come forward to show their support in the future," added Hasmah.

Also on the programme for the day was a lucky draw session with attractive prizes which included branded bicycle accessories, and the Grand Prize, a Shimano RX100 mountain bike worth about RM3,000.



Event sponsor: Yayasan Sime Darby

Thank You: Myth Studio, eyescream, 100 plus, Racemasters Resources, SMS Bike Plus, Visual Press, DeeJay Steve from LiteFM, LiteFM & Astro Arena.

*To read about Pn Hasmah's incredible story, please visit:
www.palliativecare.my/testimonials/hasmah-ibrahim*

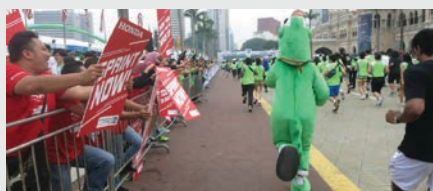
STANDCHART KL MARATHON & WORLD HOSPICE AND PALLIATIVE CARE DAY 2014

StandChart KL Marathon 2014: Committed. Confident. Courageous.

12th October 2014 - For the second consecutive year, Hospis Malaysia (HM) has been elected as one of the beneficiaries to the much anticipated annual Standard Chartered KL Marathon (SCKLM) event. The marathon has proven to serve as the perfect platform for HM to raise the much needed funds and to reach out to over 35,000 participants of the event, to raise awareness to our cause - delivering quality palliative care for all in need.

This year, we saw an increase in participation in both the **Run for a Reason (RFAR)** and the **Corporate Challenge (CR)** categories. The **CR** category gave corporations the chance to include their staff members in a team building activity that was competitive (yet fun) platform to raise funds for their charity of choice.

Funds raised will be channelled mainly into HM's patient services and training in palliative care.



Kudos to Mr Monty, HM's Paediatric Palliative Care mascot for completing the 5KM run!

World Hospice and Palliative Care Day 2014 – Who Cares? We Do!

Coincidentally, the 'World Palliative Care Day' (WPCD) – a day aimed at spreading awareness on palliative care fell on the same weekend and we took the opportunity of celebrating the day at the SCKLM 2014 event. This year, WPCD carried the theme of 'Who Cares? We Do!' The theme draws attention to the many people involved in palliative care provision worldwide, often working in challenging conditions.

Who Cares? Our Volunteers Do!



Over 50 volunteers got together to help us spread the awareness for palliative care. On race day, an army of dedicated and enthusiastic volunteers came together clad in our popular "I support" T-shirts to advocate for palliative care.



Thank you: Thank you to our runners, volunteers and to both the Standard Chartered Foundation and Dirigo Events for enabling the awareness for palliative care to be spread far and wide.

Who Cares? 400 members of the public & YB @Khairykj does!



Thanks to our dedicated volunteers, over 400 people, including Malaysia's Youth & Sports Minister, YB Khairy Jamaludin (@Khairykj) pledged their support towards the standardisation of palliative care in Malaysia and thousands more were educated on the importance of palliative care.

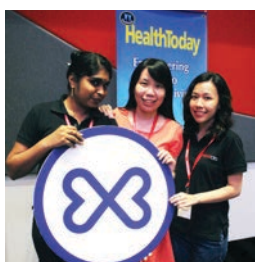
Pledge your support for the standardisation of palliative care delivery in the nation; visit this link to find out more: www.palliativecare.my/support



THANK YOU!

Hospis Malaysia is honoured to have been elected as a beneficiary of or part of the events below. These events presented us with superb opportunities to further spread awareness for palliative care and raise funds through the sale of our popular 'I Support' Palliative Care T-Shirts. Thank you to all those that dropped by our booths to show your support.

The PEAK 25th Anniversary October 2014 - Celebrating their 25th Anniversary this year, the Peak commissioned 25 artists to provide their works for a silent auction. HM would like thank the magazine for electing Hospis Malaysia as joint beneficiaries for this event and for their efforts put into raising monies for Hospis Malaysia.



HITC 2014 October 2014 - Hospis Malaysia was the sole beneficiary at Health Today's event - Health in the City 2014. Thank you Health Today for the unique opportunity to host our palliative care awareness exhibition and for the three editorial slots in 2014.

Lions Clubs International District 308 B1 Open Day October 2014 - Thank you to the organising Lions for inviting us to be part of this community event!



Mr Monty's Cheque Presentation October 2014 -Mr Monty embarked on a series of Marvellous Missions in 2014 and HM is honoured to have been the beneficiary for this great fundraising initiative!

Monash Business Club Charity Bazaar September 2014 – In their efforts to develop entrepreneurship, networking and marketing skills amongst its students, the Monash Business Club (MBC) organized a two-day Charity Bazaar. Thank you MBC for electing Hospis Malaysia as a beneficiary for this event.



#UberVWdrive - (Deejay's Kudsia Kahar and JJ Fernandez (JJ) Car sharing service Uber and Volkswagen Malaysia ran a one-day fundraising project to benefit selected charities, including HM. Thank you the radio deejays Kudsia Kahar and JJ Fernandez (JJ) for electing Hospis Malaysia as your beneficiary of choice.

Vintage Golf Showcase (VGSB) November 2014 – In conjunction with the Historic Scottish Golf (Scotland),VGSB introduces the concept of playing vintage golf in Malaysia as a platform to promote Golf Tourism in the country. Thank you VGSB for your continuous support for HM!



..and thank you to all the many individuals and corporate donors who continue to send in your contributions!

WORKING WITH OUR NEIGHBOURS

written by **Rini Vella**, Public Relations Executive, Hospis Malaysia

Training others to provide palliative care has always been a core aim of **Hospis Malaysia**. Our eight workshops that feature an international faculty of facilitators run annually and attract healthcare professionals from across the nation and the region. To complement this, *HM also provides training, support and attachment programs in palliative care for medical professionals across the region.*



The Kingdom of Thailand in recent years has become a country in *'transition from a nation of developing status, to one of international standing'* in many areas. Palliative care up to recently has been 'provided by a small number of dedicated individuals in the country' and most of the palliative care services are carried out in hospital type settings. In 2013, The Thai Palliative Care Society (TPCS) requested for and received almost \$1.5 million worth of funding from the Thai Health Promotion Foundation to develop palliative care in the country'. One of the seven projects, *'Conducting Training of Nurses in Palliative Care'* saw Associate Professor Dr Srivieng Pairojkul, president of the Thai Palliative Care Society and a group of nurses visit Hospis Malaysia for an educational tour.



“**Dr Pairojkul plans to use Hospis Malaysia's standards of services as one of the role models to emulate back in Thailand.**”



The Kingdom of Bhutan is the only country that measures its nation's wellbeing with GNH (Gross National Happiness). Only recently has this landlocked country started to open up to the outside world and has done a remarkable job in finding a balance between globalisation and preserving the *'quality of life'* of its people. With a national philosophy to make its people happy, the parallel values of palliative care – a medical sub-specialty that aims to improve the quality of life for those suffering from serious or life-limiting illnesses, is quickly being embraced in Bhutan.

In line with this, on a recent educational tour to Malaysia, **a group of officers from Bhutan requested a visit to Hospis Malaysia under the sponsorship of the Bhutan Civil Society Organization Authority (CSOA)** to both observe and learn about palliative care and the execution of its services.



In **Japan**, the use of palliative care is *'steadily growing with a trend away from palliative care units toward palliative care teams and home care.'* Palliative care in Japan is now increasingly becoming integrated into mainstream treatment. On their recent educational trip to Malaysia, student nurses from Jobu University in

Japan approached Hospis Malaysia to observe how our palliative care nurses provide professional palliative care in a community/home based setting.



References:

1. e-hospice, (2013, November). Big plans for palliative care development in Thailand <http://bit.ly/1Cr9VSC>.
2. Suita-shi, Yamadaoka (2013, January). Past, present, and future of palliative care in Japan. Retrieved from <http://1.usa.gov/15JHBio>

RESEARCH & ADVOCACY UPDATE

The Nationwide Awareness Campaign

In 2014, we launched a palliative care awareness campaign in the form of a photo exhibition that featured stories and photos of our patients, living life to the fullest despite their illness.

Why?

We aimed to educate the nation that with professional palliative care (and early referrals) patients and their families can aim to enhance their quality of life.

Collaborations with other hospices

Last year, we joined forces with the Seremban Hospice Council at the 11th Malaysian Hospice Congress and with Charis Hospice in Penang to bring the awareness to other states. Discussions have begun for possible collaborations with hospices from other states in the country.

Additionally, organisations are stepping in to offer help to spread the awareness: We were invited by Health Today Magazine to host our photo exhibition at their Health in the City 2014 event. Dialogues have also begun for a similar exhibition to be held in other key public locations in the Klang Valley.

Evaluating public opinion on palliative care

'Research is the key to understanding the context of what we do and a way to both assess past performance and study the possible success of a proposed intervention'.



In line with many international palliative care service providers and advocacy bodies, we recognise that in order to improve the quality of service and access to good palliative care, research has to be at the forefront to uphold the quality of care that we provide and to support any policy-influencing action which we may board in our advocacy plans.

To measure the current perceptions of the public about palliative care and what they may want if diagnosed with a serious illness, Hospis Malaysia have commissioned a market research agency to conduct a survey

The results from the surveys aim to provide interested stakeholders with **sufficient baseline information about the public's perception of the current state of palliative care in Malaysia** and to provide Hospis Malaysia with a basis to advocate for better access to and greater resources deployed to upgrading this area of medical specialty in the country.

Please follow us on Facebook (HospisMY) or check our website for updates on our current research, advocacy and involvements in international palliative care initiatives

MEET OUR VOLUNTEERS

Volunteers are a major asset at Hospis Malaysia. As Hospis Malaysia strains to meet its needs with limited human resource and even more limited budgets, volunteers serve as an important and valued part of the team.

By contributing their time, energy and skills, our volunteers help us generate enthusiasm, provide new skills, increase community engagement, and serve as bridges to our community.

Meet some of our volunteers and find out what they say about their experiences:



Terance Lee

"I am a medical student and have a passion for helping those in need. I have been volunteering with HM for over 3 years. Many doctors-to-be will opt for a hospital attachment and think that is all they can do to prepare themselves. In my opinion, hospital attachments may help to familiarise oneself with a hospital setting. But in order to build up communication skills with patients and other medical personnel, volunteering in HM provides a quick-learning platform like no other!"



Kai Lee



"With three months to spare till my SPM results are released, I choose to spend my free time volunteering at HM. Recently, I shaved my head bald to experience what a cancer patient may go through. Consistent with that, I wanted to learn more about palliative care and gain experience working in an office setting. My duties as a volunteer are varied. Sometimes I help support the PR Department with admin work, or help the pharmacist with inventory management."

Yuk May



"Recently, I decided to quit my job to re-evaluate my life's goals, and part of the plan was to give back to society by volunteering my skills and time to a charitable organisation. I chose HM after reviewing their comprehensive website. It seemed like a credible organisation. I help support their small team of staff with administrative functions."

Yu Wan

"I have been volunteering at HM for over a year. Recently, I helped recruit 50 of my college friends to create an impact at the SCKLM 2014 event. I have volunteered at various fundraising events for HM and helped with many administrative roles. I have learnt many new skills along the way and made many new friends!"



HOSPIS MALAYSIA INTRODUCES A NEW SERVICE: OUTPATIENT REHAB SESSIONS



At any given time, Hospis Malaysia cares for over 400 patients. Currently, HM has only one occupational therapist to attend to the needs of these patients. When a group **physical therapy session for our registered patients** was identified, a team of experienced patient services volunteers were recruited and trained to support the newly launched rehab session.

Held **every Tuesday**, the session is run and monitored closely by HM's Occupational Therapist, Raymond Toe.



The dedicated team of volunteers help Raymond monitor the progress of these patients and teach both patients and carers exercises to carry out at home.

Occupational Therapist Raymond Toe providing selected patient services volunteers comprehensive training in preparation for the newly launched outpatient rehab session.

ZI'S PALLIATIVE CARE AWARENESS RUN

January 2015 – Zi Yu Kok a Malaysian student of Glenunga International High School, in Adelaide, Australia organised a palliative care awareness run recently.



"When it came to choosing a project for my International Baccalaureate diploma, I decided on a fundraiser for HM. I choose this because of the help HM had provided to my late-grandmother. I also realised that most people did not have much idea as to what palliative care is. I decided to take this opportunity to help HM raise awareness and funds by hosting a charity run. My idea of a charity run was to have people unite and running towards a great cause- to better access to professional palliative care for those in need." – Zi Yu Kok

UPCOMING EVENTS & UPDATES

HOSPIS MALAYSIA'S 14TH EDITION – CHARITY TREASURE HUNT

Save the date! The much anticipated HM Annual Charity Treasure Hunt is set for **18th April 2015**.

The 14th edition of our hunt will see hunters sifting through a series of clues in and around the Klang Valley. Every year, the event brings round groups of individuals for a day of brain-teasing fun! Stay tuned as we will be providing more information through our website and Facebook pages on how you can take part in this much anticipated event!



LITTLE STARS - A MOVING PICTURE ADVOCACY PROJECT FOR PAEDIATRIC PALLIATIVE CARE



Life is short, value every moment.

It has been a year since the filming of the Malaysian leg of Little Stars took place in Malaysia. Moonshine Movies, the producers of Little Stars have since completed filming in nine countries - the USA, South Africa, India, Australia, Malaysia, Italy, Jordan, the UK

and Russia. Ahead of the release of the one-hour film, short-films are currently being released over YouTube every two weeks, **each film providing excellent introductions and insights into paediatric palliative care for children.**

This series of short films are part of a global advocacy and awareness project to raise the level of awareness for paediatric palliative care. **We need your help with sharing these films as broadly as possible.** The series will comprise a one-hour feature film for television, with broadcast confirmed through Al Jazeera Documentary Channels worldwide. The project will also be broadly available through Pay TV, Video-On-Demand services including iTunes and NetFlix, DVD, iOS App and online. **To find out more or to view the short films,** please visit www.littlestars.tv

WOMEN'S WEEKLY: GREAT WOMEN OF OUR TIME



won - (in her category: Health, Sports & Wellness!)

As a palliative care doctor, Dr Chong ensures patients with life-limiting illnesses can access quality palliative care. She co-founded the Malaysian Paediatric Palliative Care Reference Group to coordinate service,

October 2014 - Hospis Malaysia is proud of our palliative care doctor, Dr Chong Lee Ai who participated and

education & training as well as to make useful data available to healthcare providers. She also spearheaded the Malaysian leg of Little Stars (www.littlestars.tv. See above)

Her goal is to create better public awareness that can motivate patients to demand for their rights. You too can help Dr Chong and Hospis Malaysia achieve our goal of creating better public awareness for palliative care. **Petition your support towards the future development of palliative care in Malaysia today!** For further information, please visit: www.palliativecare.my/support