

## RANKING **PALLIATIVE CARE** ACROSS THE WORLD

By Rini Vella, Advocacy Executive

A pillar of focus for governments around the world is to improve the quality of life for its citizens and in doing so; governments must also consider how to help their citizens achieve a good pathway to death. Palliative care is a medical subspecialty for people with serious illnesses. The focus is to provide patients with relief from the pain and symptoms and stress of an illness while considering the psychosocial needs of their family or caregivers. The Economist Intelligent Unit (EIU) has assessed the availability, affordability and quality of palliative care available to adults across 80 countries. Countries were scored out of 100 on 20 indicators in five categories: palliative and healthcare environment, human resources, affordability, quality of care and the level of community engagement.

### COUNTRIES LEADING THE PATH

'The United Kingdom (UK) ranks first in the 2015 Quality of Death Index; its ranking is due to comprehensive national policies, the extensive integration of palliative care into the National Health Service, a strong hospice movement, and deep community engagement on the issue. The Quality of Death Index, commissioned by the Lien Foundation, a Singaporean philanthropic organisation, is based on extensive research and interviews with over 120 palliative care experts from across the world', states the EIU. Australia and



New Zealand ranked second and third respectively. Taiwan is leading the way, ranking first in Asia and 6th worldwide. Taiwanese palliative care is widely available, affordable and comprehensive.

### IN THIS ISSUE

#### EDITORIAL NOTE

Ranking palliative care across the world 1

#### PALLIATIVE CARE NOTES

Planning ahead – What is an advance care plan? 3

#### PAST EVENTS

Standard Chartered KL Marathon 2015 4  
Voices for Hospices 2015 6

#### THANK YOU

5

#### EDUCATION

The importance of incorporating palliative care training to healthcare education curriculum 8  
Empowering palliative care through education 9

#### FEATURE

Running to Remember - An exclusive interview with Grace Loo 10

#### WORLD HOSPICE & PALLIATIVE CARE DAY

Little Stars: Accomplishing the extraordinary in the face of serious illness 11

#### UPCOMING EVENTS & UPDATES

2016 Calendar gift box set for charity 12  
Charity Treasure Hunt 2016 - Coming soon 12

## COUNCIL MEMBERS

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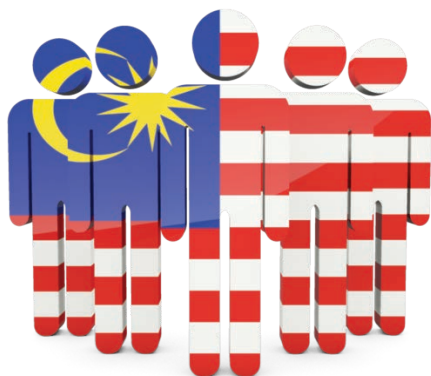
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### PALLIATIVE CARE MALAYSIA an initiative by Hospis Malaysia

Website: [www.palliativecare.my](http://www.palliativecare.my)  
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continued from page 1



## SITUATION IN MALAYSIA

Malaysia is placed **38th** out of 80 countries in this report.

The report revealed that there are only five public hospitals with palliative care facilities and that more funds are needed to expand public infrastructure to other hospitals and rural areas. Inadequate public funding in the country has increased the call for

charitable institutions to deliver palliative care services to the community. A more serious issue in the field of palliative care nationwide is its severe shortage of specialists. There are currently only seven certified palliative care experts in the country. This shortage of experts is further intensified by the fact that 'most medical schools in the country do not offer compulsory courses in palliative care, resulting in a limited understanding of the topic within the medical community' states the report on Malaysia.

Patient choice and autonomy are considered key in palliative care, these aspects are generally not valued by healthcare providers who 'tend to share information about diagnosis and prognosis with families, and only inform the patient if requested' states the report. Patient satisfaction surveys can be meaningful and essential sources of information for identifying gaps and developing an effective action plan for quality improvement in healthcare organisations. According to the report, the use of such surveys is rare in Malaysia.

“A more serious issue in the field of palliative care is its severe shortage of specialists. There are currently only seven certified palliative care experts in the country.”

There is a stark absence of officially-prescribed minimum standards imposed on our palliative care service providers. On the plus side, access to opioid or pain relieving medication is good since it is available in public hospitals after access regulations were scaled back. Public awareness has improved over the last decade but detailed understanding of palliative care is limited. Charitable organisations and NGOs 'rely on a robust network of voluntary support, although training is minimal'.

The full report is available for download here: [www.economistinsights.com/healthcare/analysis/quality-death-index-2015/fullreport](http://www.economistinsights.com/healthcare/analysis/quality-death-index-2015/fullreport)

**Help Hospis Malaysia understands your perceptions on palliative care so that we can continue to improve on the quality of care to those in need. Have your say. Participate in our 15 minutes survey before 31st December 2015! [hospismalaysia.org/publicsurvey](http://hospismalaysia.org/publicsurvey)**

## PLANNING AHEAD – WHAT IS AN ADVANCE CARE PLAN?

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



### Advance Care Planning: Decision making for the end of life

Talk to your family and complete an advance care plan so that your wishes for care at the end of life are known.  
Find out more at: [palliativecare.my](http://palliativecare.my)

There are many times in my life when I think about how life will be like if I am struck by a serious illness. Being independent and being in control of my life is what I value and treasure. What if I lose control as a result of my illness? What if I cannot speak to my loved ones as a result of my illness? What if I am forced to undergo medical treatment that is against my wishes? I shudder with fear just thinking about it.

An advance care plan is a process of planning for your future health. It involves talking with your loved ones and healthcare professionals about your personal beliefs and values and how that may affect your healthcare preferences in difficult medical situations. It is also about thinking who among your loved ones can be your voice if you become seriously ill one day.

Planning ahead can help to guide healthcare professionals and loved ones to make the best decisions about your care once you can no longer speak or decide for yourself. In fact, advance care planning discussion can take place even for a healthy person. As medicine advances, this sort of planning is important because more people are living longer with chronic illnesses.

The discussion on your future health should be an ongoing process. You can change your mind about your healthcare preferences as circumstances in life change.

However, remember to update your wishes with your loved ones and your healthcare professionals. It may be helpful to put your preferences in writing. Although what you put in writing is not legally binding in Malaysia, it will hopefully serve as a platform for others to act according to your wishes.

As for whom you can appoint as your voice, it can be a family member or a friend. The most important thing is to choose a person whom you trust and know will act in your best interest should you become too ill to speak for yourself.

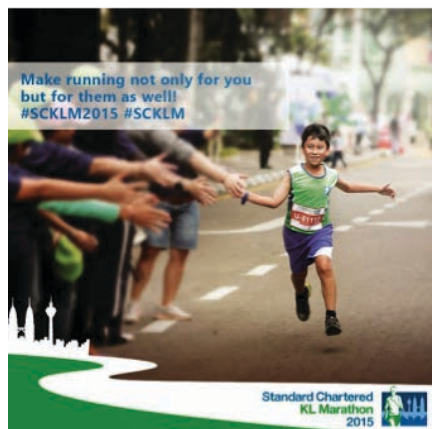
Although this article talks about the benefits of planning ahead, it is absolutely fine if you are not ready or does not feel that it is important at this point in time. For those of you may want more information, talk to your healthcare professionals about how to go about it in planning for your future health and care. ■

#### WHERE CAN I FIND MORE INFORMATION?

**5 WISHES** – The five wishes helps you express how you want to be treated if you are seriously ill and unable to speak for yourself. Available at: [www.agingwithdignity.org/five-wishes](http://www.agingwithdignity.org/five-wishes)

Download an information brochure on **Advance Care Planning** at [www.palliativecare.my/about/resources](http://www.palliativecare.my/about/resources)

## STANDARD CHARTERED KL MARATHON 2015



Hospis Malaysia is grateful for its inclusion as a charity beneficiary of Malaysia's largest sporting event, the Standard Chartered KL Marathon (SCKLM) for the past three years. Through the marathon's Run for a Cause and Corporate Challenge categories, marathoners are enabled to raise funds for the charity of their choice.

The SCKLM has come to serve as a fruitful venue for our supporters to get fit and engage in healthy competition whilst showing their support for Hospis Malaysia through their fundraising and awareness raising initiatives leading up to race day. This year, through the marathons 'Run for a Cause' and 'Corporate Challenge' categories, 120 individuals and 20 corporates elected Hospis Malaysia to benefit their fundraising and CSR efforts. Despite the cancellation of the marathon due to aggravated haze conditions,

Hospis Malaysia is deeply appreciative and moved by all our supporters and the marathon organisers for the overwhelming support and remarkable fundraising efforts to ensure Hospis Malaysia is able to continue the important work that we do.

These were some of the reasons runners elected Hospis Malaysia as their charity of choice:

#### Agnes Lim

"I'm inspired to take up the challenge and Run for a Cause because when my father was battling cancer, the staff at Hospis Malaysia were very professional in providing good care for him. My aim is to be able to extend as much help as I can to this organisation for the commendable work they do."



#### Lim Li Ann

"When my father was battling pancreatic cancer, Hospis Malaysia extended their helping hands. In this brief encounter, they made things easier for us. When we found out more about this amazing organisation, Dad wanted to do something for them. With this pledge, I hope to express our gratitude, and also to do my part, to pay it forward."



#### Abdul Aziz Draim

"Running is painful, yet I choose to do it. For some people, living is painful but they don't have a choice because they suffer from life-limiting diseases such as cancer, heart disease, kidney failure. Hospis Malaysia gives them palliative care to enable them to live their life to the fullest, like you and me. And this service is FREE. But for it to remain free, I need you to donate to the cause.."

#### Hubert Gan

"Perhaps one of the biggest misconceptions about palliative care is to associate it with end of life care for the dying. Through Hospis Malaysia, I realised the importance of the care provided by them to alleviate pain and provide utmost comfort to patients with life limiting illnesses for as long as life remains. I pledge to raise donations to show appreciation and support for Hospis Malaysia and hope that more will be aware of this charitable organisation."



# Thank you



**'Let's Beat It!' Dinner, August** – CARES hosted a fundraising gala dinner with the objective to help raise funds and create public awareness for charities. Hospis Malaysia was elected as one of the beneficiaries for this dinner event.

**Malaysian Medics International Summit, August** – to prepare Malaysia's medical students for their future medical careers in Malaysia. Hospis Malaysia participated to create further awareness about palliative care and the role of hospices to Malaysia's burgeoning medical students.



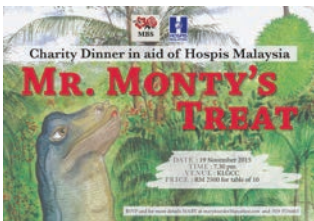
**International ZOUK day, September** - A group of passionate Brazilian Zouk dancers banded together to celebrate the Malaysian celebrations of 'International ZOUK day 2015' with a series of flash-mob dance routines at Publika.

**Hospis Malaysia's Donate a Brick Project, October** – A group of donors participated in Hospis Malaysia's Brick Inscription Day inscribing messages of hope and inspiration on their bricks which are cemented permanently on Hospis Malaysia's walls. If you would like to participate please visit [hospismalaysia.org/support-us/donate-a-brick](http://hospismalaysia.org/support-us/donate-a-brick) for further information.



**BV Community 4 Humanity Day, November** - The community at Bangsar Village provided a platform to raise funds and awareness for their organisations.

**ECS ICT, November** - The organisation donated three desktop computers to Hospis Malaysia as workstations for our nurses, to support its ongoing effort to go paperless on its patient information management system.



**Malaysian British Society Charity Dinner, November** – A society which brings together Malaysians and British nationals living in the country, this was an annual get-together with a purpose – this year, they elected Hospis Malaysia as the beneficiary of proceeds from the event.

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

## VOICES FOR HOSPICES 2015 - 'THE GIFT OF RELATIONSHIPS'

by Rini Vella, Advocacy Executive



**16<sup>th</sup> October, Majestic Hotel, Kuala Lumpur** - Earlier this year, Hospis Malaysia commissioned a study to find out how many people know what palliative care is. Preliminary findings indicate more than 90% of the population had never heard of the term 'palliative care'. Once every two years, hospices and palliative care providers around the world celebrate a unified day of action aimed to offer support to palliative care under the umbrella of 'Voices for Hospices', a day to raise funds and awareness of palliative care services and its development. In tandem with global celebrations, Hospis Malaysia celebrated the day with its 'Voices for Hospices 2015' charity dinner themed 'The Gift of Relationships'. The focus of this year's dinner was to further increase awareness and engage our guests in the evolving field of palliative care globally and where we are in Malaysia concerning these developments.

To develop healthy relationships is a key component of wellbeing and can contribute to one's quality of life. Relationships between the patient and their family or caregivers are a fundamental element in the practice of palliative care that aims to relieve suffering and to promote quality of life. "True happiness comes from being with family and having true friendships. And when we are faced with a life limiting illness this is when we really value this precious gift of relationships", said Datin Kathleen Chew, the Organizing Chairperson of the charity dinner. This theme echoes the sentiments of the palliative care symbol whose core concept embraces the significance of relationships and serves to remind us that every person suffering a life-limiting illness such as cancer, organ failure, or progressive neurological disorders should not have to go through that journey alone.



Guests were entertained that night by Najwa Mahiaddin, famous for her sultry vocals, and empowering lyrics. The highlight for the evening, young and old, was a social media wefie/selfie photo competition including paraphernalia carrying the palliative care symbol. The symbol, developed by Hospis



*Laurence Lien, Lien Foundation*

Malaysia just over a year ago, created an identity for palliative care. This identity, with increasing global acceptance, can mobilise resources to ensure that palliative care will one day be accessible to all in need.

The guest speaker for the evening was Mr Laurence Lien, Chairman of the Lien Foundation, a philanthropic organisation with an active role in the development of palliative care in Singapore. During his speech, Mr Lien addressed the difficulties of confronting death and doing it right. "In many societies around the world today, we are poorly prepared for end of life issues. We are fraught with whether to intervene or not to intervene. We ask for more to be done, even when more may be futile and may not improve the quality of life. What modern medicine is very good at doing is to keep us alive. But the problem is they are not very good at keeping us well to the very end". Speaking on assisted dying, "It is my strong belief that if you do palliative care well, most people would not



want to hasten their death and will generally experience an improved quality of life”, he added.

Mr Lien went on to share how his foundation supported their local hospices in raising awareness for palliative care. “In Singapore, most hospices are run as non-profit organisations, and they were struggling in this area – death was a taboo topic, we (Lien Foundation) wanted to change this. Palliative care units of hospitals and hospices were crying out not just for resources, but for recognition and attention of their important role. We gave out grants to expand care into the community, and to increase hospital beds at palliative care units. Then we wanted to do more. It was not enough to just give resources to programs; we had to address issues at the root cause. So, we invested a lot on advocacy and a lot on capacity building through our collaboration with National University Hospital (NUH) and Duke University in palliative care training and education.”

The event sparked an air of optimism and gave a clear call to action to all present that night: “Become a palliative care advocate”. In the words of Dato’ Richard Robless, Chairman of Hospis Malaysia, “Like all things new, palliative care needs advocates to

spread the word and to become the voices of the voiceless” and as Mr Lien so aptly put while addressing our guests, “I think you are here because you see something important that is worth growing and worth advocating for.”

Hospis Malaysia is grateful to those who joined us that evening to celebrate this significant event and to support us in our efforts to achieve our vision of influencing policy makers to enact legislation to set minimum standards of palliative

care services and to take on the responsibility of ensuring quality palliative care is accessible and made available to all those in need. ■

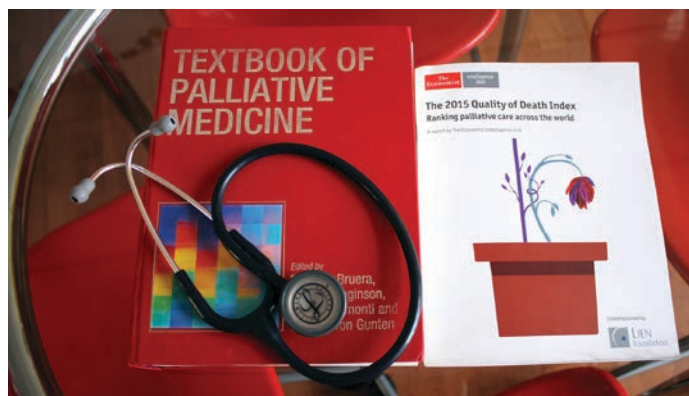


*Emcees Kate Millett and Datuk Yasmin Yusuff taking a selfie*



# THE IMPORTANCE OF INCORPORATING PALLIATIVE CARE TRAINING TO HEALTHCARE EDUCATION CURRICULUM

by Rini Vella, Advocacy Executive



## The need for a holistic approach to care

Population ageing and the increasing incidence of non-communicable, life-limiting diseases such as cancer, organ failure, or certain degenerative neurological diseases is bringing about significant challenges to the way most health care services operate. Modern healthcare systems tend to focus on cure and treatment to reverse a disease rather than on the individual patients' preferences, needs or values.

When a patient is diagnosed with a life-limiting illness and is told that their condition is irreversible, often, apart from physical symptoms that the patient may be suffering, the patient and the people around them will experience emotional anxiety and psychosocial issues. And if these issues are not addressed in totality, it can affect the well-being and quality of life of the patient.

Research shows that treatment centred around the patient, and clinical decisions guided by what the patient considers as important often achieves better patient outcomes. Palliative care addresses the physical, emotional, psychosocial aspects of a patient's life. It aims to improve the quality of life of the patient and to facilitate a support system for family members

to help them cope with their loved one's illness. And this is found to be currently still lacking in our healthcare services and is attributed

largely to the approach taught in medical schools.

## The palliative care approach

The palliative care approach challenges the boundaries of medicine. "Is palliative medicine a medical sub-specialty or simply an approach to care that should be adopted by all healthcare professionals?" asks Dr Ednin Hamzah, Medical Director of Hospis Malaysia. Palliative care ask us about the fundamentals as to how we care for our loved one and begs the question of the clinicians – 'should you treat the patient the same way as if you would treat your loved one? Shouldn't all healthcare providers then practise the palliative care approach as a core part of their practice?' adds Dr Hamzah.

## Integrating palliative care into all healthcare education and training

The palliative care approach should be a core skill of every clinician at the hospital and community level and made a mandatory part of curriculum for not only nursing and medical schools but also to all allied healthcare professionals such as physiotherapists and psychologists. In Malaysia, awareness of the benefits of palliative care is low, few patients are referred to palliative care, and often, referrals are late in the course of the illness.

## The situation in Malaysia

Currently, there are only seven palliative care experts in the country. 'Most medical schools in the country do not offer compulsory courses in palliative care, resulting in a limited understanding of the topic within the medical community.' For the few medical schools that do offer palliative care training, exposure to the subject is limited to just a few days out of their entire undergraduate teaching. Most nursing postgraduates do not receive any exposure to palliative care.

Hospis Malaysia is currently the only organisation conducting regular palliative care courses nationally through a series of structured workshops in collaboration with the Asia Pacific Palliative Care and Hospice Network (APHN). While these workshops carry the endorsement of their professional colleagues from the region (through the APHN), and most medical schools looking to include palliative care teachings in their curriculum will invite Hospis Malaysia's doctors to facilitate these lectures, there is still a lack of an officially-prescribed palliative care training curriculum in the country.

Issues faced by most patients such as adequate pain and symptom management, nutrition, communication or emotional well-being are central to improving ones quality of life. If you or your loved one had a serious illness, what type of care would you want to receive from your healthcare professionals? Would you want them to focus on the person with the illness, or just on the illness? Do you know if they have been trained to do that? ■



# EMPOWERING PALLIATIVE CARE THROUGH EDUCATION

By Wendy Loo, Public Relations Executive

Presented by: *Prof John Ellershaw*, Medical Director of the Marie Curie Palliative Care Institute (MCPCI) and Professor of Palliative Care at University of Liverpool; *Dr Ruthmarijke Smeding*, Snr. Educational Consultant of MCPCI and Director of Pall Ed; *Dr Ednin Hamzah*, Medical Director of Hospis Malaysia.

## Training the Teachers for Palliative Care Workshop, 26-31 July

“Give a man a fish and you feed him for a day; teach a man to fish and you feed him for a lifetime.” This old proverb exemplifies the importance of education, and how education can not only help spread knowledge, but also empower other people. Hence the importance of this workshop, the first of its kind in Malaysia. Organised by Hospis Malaysia and the Marie Curie Palliative Care Institute, Liverpool, the course aims at providing palliative care professionals with knowledge and skills on how to teach, so that attitude, knowledge and skills could be delivered more effectively to others.

Distinctions were made between teaching aims and learning outcomes. The intensive and experiential workshop saw its participants through a journey of self-discovery of how they learned, which learning style worked best and worst for them, and how to apply theories of learning style to different groups of participants in order to be more effective teachers.

Established in 1994 in the UK, the course has since been conducted in various other countries. “Our palliative care professionals should be exposed to and given the opportunity to have the same



level of skill sets that those in other countries have. It is not enough for our few palliative care doctors and nurses to only be able to provide palliative care. They need to be able to teach it, model it and be leaders in their respective areas,” said Dr Hamzah.

“Doctors are expected to know how to teach, even though all they have is medical knowledge,” said Prof. Ellershaw. “Therefore, it is important to train healthcare professionals on how to impart their knowledge in the most effective ways to ensure that the knowledge is then used by the student in their practise of medicine. And if this knowledge is not taught in relation to actual practice, then you would not have achieved what you set out to teach.” He quoted Sir William Osler, famously known as the founder of modern medicine: “He who studies medicine without books sails an uncharted sea, but he who studies medicine without patients does not go to sea at all.”

Dr. Richard Lim, national advisor on palliative medicine at the Health



Ministry and heads the Palliative Care Unit at Selayang Hospital, agreed with this viewpoint. “We need to educate people first before we are able to see [any changes or progress],” he said. “It was a prolific course, and from it, we could see the necessity in educating healthcare professionals and see how [this education] spreads to the public. The different approaches [taught in the workshop] are not what we are used to, and it could be helpful in communicating with other people.” This is especially so in the field of palliative care, where the number of professionals are low in Malaysia. There are massive gaps in knowledge across the country, and many healthcare professionals are still unaware of palliative care and the need for this approach by patients with life-limiting illnesses. ■

## RUNNING TO REMEMBER

An extract from an exclusive interview with Grace Loo



**I am running for**



#GraceTMBT100km

**"T**he Most Beautiful Thing" or "TMBT" ultra-trail marathon race is a 100km hike for 30 hours, where participants brave harsh terrains, severe isolation and extreme weather conditions.

Grace Loo, one brave lady took this challenge to flex her fundraising muscle for Hospis Malaysia, a charity permanently etched in her heart, when she witnessed her dearest mother slowly succumb to cancer. "Losing mum had a terrible effect on my family. She was the love we all revolved around. She didn't take kindly to allowing any chance for old age to have the final say. I grew up watching her live her life with an iron will. It's for this reason that her illness came as such a blow to her and us."

Although Grace had been relatively active in adventure sports most of her life, she only started long distance running last year. Engulfed in a deep cocoon of grief, anger, and frustrations beyond what she could handle, Grace realised she "needed to do something" to turn her life around. She decided to run. After one ponderous mile, she found herself in pain, physically and emotionally ruined. "It was unbearable. Not only my body and legs refused to co-operate, the immense weight of my grieving heart made it an almost impossible feat to hold myself together along the run," recalls Grace.

Although it brought pain, it also brought upon a much-welcomed sense of relief. With each run, the burden

from grief became lighter. In Grace's own account, "watching cancer slowly extinguish a fire as bright as mum's was something she and her family hoped they would never have to see."

Confused and overwhelmed, her family felt utterly powerless as they witnessed the rapid deterioration of her mother's condition. There was nothing they could do except watch, knowing they were merely waiting in line at death's door. "It reached a point where we were just going through the motions." Hospis Malaysia taught Grace the meaning of caring with compassion.

"The Hospis Malaysia staff provided round-the-clock support and delivered specialist palliative care with such loving kindness, to not just Mum but also our family through this very difficult time. Palliative care trained nurses came to give Mum and us all the support and care we needed. The staff at Hospis Malaysia were like angels; they brought so much care and comfort to Mum and our family."

**“Facing the end is never easy, mostly because those facing it lack any say in the matter. But this does not mean that there must be suffering.”**

"Mum held my hand to wake me, waved briefly and smiled before she took her last breath. She left peacefully," said Grace. "No noise, no machines, just quietness. She was in her own room at her own home and we knew she was in the right place."

"Hospis Malaysia's team were so supportive – I can't thank them enough for what they did for my family, and for other families just like ours. Without them, our stories would be very different."

Running TMBT is about Grace and her tireless stride to leave a trail of influence in making an indelible difference in palliative care scene in Malaysia. "That's what #GraceTMBTchallenge is all about – making a difference. It's a very special feeling." Grace's fundraising labours will be channelled towards funding round the clock palliative care and practical support to all in need, when it is needed in the community. "I will never be able to fully thank Hospis Malaysia for what they did, but I can certainly try to help them to do the same for others." ■

# LITTLE STARS: ACCOMPLISHING THE EXTRAORDINARY IN THE FACE OF SERIOUS ILLNESS



## PALLIATIVE CARE FOR CHILDREN WITH LIFE-LIMITING ILLNESSES

Over  
**20**  
million

children worldwide could benefit from palliative care but they have no access to the service.



About 80,000 babies, children and young adults live with life-limiting illnesses in Malaysia.\*



The aim of palliative care is to relieve suffering and promote quality of life.



Illnesses that may require children's palliative care include cancer, severe cerebral palsy, neuromuscular conditions, congenital anomalies or extreme prematurity.



Age appropriate, sensitive but honest communication with children is the cornerstone of children's palliative care.



A child's quality of life is vastly improved when the symptoms of their illness are well managed. This may require the use of opioids to adequately control pain.

Source: International Children's Palliative Care Network (ICPCN)  
\* Needs assessment for children's palliative care in Malaysia (2015) by Stephen Connor, PhD - Senior Fellow to the Worldwide Palliative Care Alliance

The International Children's Palliative Care Network (ICPCN) estimates that twenty million children worldwide suffer unnecessarily due to the physical and psychosocial issues that come with a serious illness. In Malaysia, it is estimated that about 80,000 babies, children and young adults live with life limiting illnesses in Malaysia. These children can greatly benefit from palliative care, but access to such services remains an issue. Children's palliative care is the total care of the child's body, mind and spirit and is a response to the suffering of a child and their family facing serious illnesses.

Hospis Malaysia has been instrumental in the development of paediatric palliative care nationwide. During her visit to the charitable organisation in 2012, The Duchess of Cambridge, Kate Middleton lent support to the development of paediatric palliative care in the country by indicating in her maiden speech

abroad, how palliative care provides a lifeline to these children and their families. During this visit, she also witnessed the Minister of Health launch the National Paediatric Palliative Care Initiative with Her Royal Highness Raja Zarith Sofiah Binti Almarhum Sultan Idris Shah as the royal patron of the initiative.

"Since then, there has been an impetus by paediatricians around the country to develop and improve palliative care services for our children. Our Royal Patron has been a great advocate in her state of Johor. Palliative care services for children are now more accessible there. But although policy makers have been approached to prioritise paediatric palliative care in the nation's healthcare services, there has been minimal progress in this area since the launch in 2012. There is no will to establish a national framework," says Dr Ednin Hamzah, CEO and Medical Director of Hospis Malaysia.

Awareness for this medical sub-speciality remains low amongst healthcare providers and the general public. "In Malaysia, data is scarce; we don't know how many children there are with life-limiting illnesses that need help." Nationwide, it is estimated that thousands of children are suffering from such illnesses, such as cancer, HIV/AIDs, severe cerebral palsy, neuromuscular conditions, congenital anomalies or extreme prematurity. But referrals to palliative care providers are in the low hundreds. "Who is seeing these patients? What type of care are they receiving? What can we do more to help them?" asks Dr Chong Lee Ai, a palliative care doctor with special focus on paediatrics, at Hospis Malaysia.

To address this, Hospis Malaysia in collaboration with the Department of Paediatrics, University of Malaya hosted the Malaysian premiere of an advocacy film '**Little Stars: Accomplishing the extraordinary in the face of serious illness**' – in an effort to increase awareness of the unique needs of children's palliative care and how lives can be transformed with proper access to palliative care.

With the support of CIMB Foundation, three paediatric patients of Hospis Malaysia and the initiative spearheaded by the Sultanah in Johor are featured in this documentary together with its accompanying short stories. The film aims to put children's palliative care on the global media and public health agendas.



continued from page 11

The powerful documentary and fifteen short films celebrate how children's lives worldwide are transformed by making the most of every moment, with the support of their loved ones and their palliative care teams.

In a panel discussion on the current state of children's palliative care in the country, Dr Yap Tsiao Yi, Paediatric Oncologist at the University of Malaya highlighted the need to introduce the teaching of palliative care at medical and nursing schools. "We teach so much in medical schools on how to do a medical examination but little is taught at how to deal with end of life issues". "How do you talk to someone when their child's life expectancy is limited?" "In the medical profession – we are taught how to save lives. It is one intervention after another after another – where do you draw the line and stop intervening and begin conversations about what the child or family may want?"

Dr Richard Lim, Head of Palliative Care Unit at Hospital Selayang, and National Advisor on Palliative Medicine for the Ministry of Health, highlighted that the challenges faced by the Ministry in pushing the initiative further were the lack of human resources, funding and awareness.

Joan Marston, CEO of the ICPCN commented when she watched the film at a separate screening: "Far too



Together with the International Children's Palliative Care Network (ICPCN), World Hospice Palliative Care Alliance (WHPCA) and Moonshine Movies, Hospis Malaysia is inviting organisations, activist and individuals to host a screening of this documentary film

– **Little Stars: Accomplishing the Extraordinary in the Face of Serious Illness** or to use the short-films for public education or advocacy. To find out more, visit [www.littlestars.tv](http://www.littlestars.tv)

many people either do not know of the suffering of children with life-limiting illnesses, or who knowing; don't care enough to do something to change it. "Watching the children, families and care programmes in the *Little Stars* films, I have realised that it is the stories that the children and families share that will make a difference and could do so much to change indifference into action". ■

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## CHARITY TREASURE HUNT 2016 - COMING SOON

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