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EDITORIAL NOTE

BETTER ACCESS TO PALLIATIVE CARE

By **Dr Ednin Hamzah**, CEO & Medical Director, HM

There are two certainties if we are to spend any time on this earth. First, is our birth and the second, our departure from this life. Whilst both could occur naturally and without any medical intervention, (ie: natural birth and a peaceful death), society dictates and modern medicine teaches that we need to do all that is possible to ensure that the birth of a baby and the health of the mother is free from any medical complication. And that life is prolonged for as long as possible with a variety of medical intervention, often at the expense of unnecessary greater suffering.

In 2010, the Economist Intelligence Unit placed Malaysia 33rd out of 40 countries in a survey on "Quality of Death" which looks at the quality of end of life care. The UK was ranked 1st and all other Asian countries surveyed - Taiwan, Singapore, Hong Kong, Japan and South Korea were ranked higher with the exception of India.

When faced with pain and suffering from a life limiting illness, palliative care can provide patients and families better pain and symptom control, improved social, psychological and spiritual care. In the practice of palliative care, clinicians also help facilitate discussions with the patient about care preferences.

In 2010, a landmark paper in the New England Journal of Medicine by Temel et al showed that palliative care in conjunction with anti-cancer treatment in non-small cell lung cancer showed not just improved quality of life but also improved survival compared to just anti-cancer treatment. Such a major development suggests that palliative care has benefits beyond the care of patients only at the end of life.

There is now an increasing body of evidence to support palliative care as a means to relieving suffering for patients and families affected by life limiting illness. In May 2014, Malaysia was a sponsor to a World Health Organisation resolution for palliative care and this year, we also spoke positively in support of palliative care at the World Health Assembly.

Whilst the Ministry of Health has set up several palliative care services in parts of the country and recognised palliative medicine as a medical sub specialty, the reality is that for most Malaysians, access to good palliative and end of life care is still very limited.

In Malaysia, the main illnesses that could benefit from palliative care include cancer, organ failures, degenerative neuromuscular diseases, HIV / AIDS and several categories of diseases affecting children. Yet, in a recent public survey, more than 90% of Malaysians have not even heard about palliative care.

An indirect method of measuring the level of palliative care activity is to measure the use of morphine in the country. Morphine is classed as an essential drug for cancer pain and all doctors should be aware of the proper use of it. In 2011, Malaysia's consumption was 1.48 mg / capita with the global mean at 6.28 mg / capita. This is a drug that is readily available in the country, and has evidence to demonstrate that it is effective in managing pain for cancer patients. Yet most doctors are not aware of its proper use to relieve suffering.

Here in Malaysia, palliative care is often delivered late if at all. Patients and families and even most doctors are not aware of what benefits it can give and many doctors refer at a very late stage. In most towns and villages in the country, palliative care is simply not available.

In some neighbouring countries, apart from a multitude of professional palliative care services, governments have also introduced legislation to support palliative care and end of life care. Advanced care planning also allows patients to state their care preferences if they become critically ill.

Palliative care services should be available in all hospitals and in the community. It should be a core component of all undergraduate medical and nursing curriculums and there should be public education to increase awareness and correct misconceptions.

As demonstrated, palliative care does not cost more money and actually has cost benefits as it could reduce unnecessary medications, investigations and reduce hospital stay. The Ministry of Health Malaysia has supported the call for palliative care internationally. However, it is time that the public is made aware of how it intends to make both adult and paediatric palliative care accessible to every citizen of Malaysia.

[For more information about palliative care, visit www.palliativecare.my]

> “No act of kindness, no matter how small, is ever wasted.
>
> - Aesop

LOVE OF HUMANITY

By **Dr Ednin Hamzah**, CEO/ Medical Director, Hospis Malaysia

Society often reflects on what is believed to be the notions and values of humanity in a generally positive perspective. These revolve around love, kindness, honesty, respect, tolerance and other virtuous values. Civil society has strived to ensure that these values are the cornerstone of the foundations of our community, from an individual level to the highest levels of government.

Another virtue often hidden away from public gaze is that of philanthropy. Etymologically it means ‘love of humanity’ in the sense of caring, nourishing, developing and enhancing ‘what it is to be human’ on the part of benefactors (by identifying and exercising their values in giving and volunteering) and on the part of beneficiaries (by benefitting).

Many philanthropists do their work quietly and require no recognition or even acknowledgement in their work or efforts. A sense of purpose or achievement of a good deed done is often enough. Many seek anonymity for their deeds.

Palliative care in Malaysia has been fortunate to have its share of philanthropists. The obvious ones are certainly our donors some of whom donate so generously, willingly, repeatedly and anonymously. Others include our volunteers who form the largest workforce for many charitable causes in the country.

The founding and further development of Hospis Malaysia has been dependant on the efforts of so many people over the past two decades and more. The inspiration and ceaseless work through the late Dato Dr Sir Peter Mooney created the initial template that has served us so well. This was augmented by the efforts of our volunteers who served in various capacities, from the boardroom to funding and to direct patient care.

From its unassuming beginnings as an organisation borne out of a wish to assist in helping patients and families, in caring for those who were facing life limiting illness in the Klang Valley, Hospis Malaysia has become a national voice for palliative care.

Presently Hospis Malaysia provides care for between 500 – 550 patients at any point in time and about 2500 patients yearly. In education and training, we provide palliative care teaching at under and post graduate levels to 8 medical schools as well as training specialist doctors for the Ministry of Health. In collaboration with the Asia Pacific Hospice Palliative Care Network (APHPCN), our seven annual workshops helps train healthcare workers from all over Malaysia and from our neighbouring countries. In the past year, we are working on increasing awareness of palliative care to the national public through various initiatives.

There has been no government funding for any of Hospis Malaysia’s programmes in recent years and we are wholly dependent on the virtue of philanthropy from those who are supportive of palliative care. Whilst there will always be those who crave recognition and rewards for their contribution to a cause, we are forever indebted to those who simply wish to help without as much as even a wish to be thanked.

The late Dato Dr Sir Peter Mooney served as an inspiration to the founding of Hospis Malaysia in 1991 and served as Chair, Council Member and Honorary Adviser until his passing on 27th April 2015.

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PALLIATIVE CARE MALAYSIA
an initiative by Hospis Malaysia

Website: www.palliativecare.my
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WHAT TO SAY AND DO WHEN A LOVED ONE HAS A SERIOUS LIFE-THREATENING ILLNESS

By Dr Sylvia McCarthy, Deputy Medical Director, Hospis Malaysia

How do you support your loved one who has a serious life-threatening illness?

Everyone reacts differently to having a diagnosis of a serious illness. It is a time of great emotional distress. There is no right or wrong way to cope with what is happening. Some may be eager to share their feelings and discuss their experiences, while others may be quiet and become withdrawn. Just as you, as a carer, may want to protect your loved one from more distress, they may also be trying to protect you. This can lead to a breakdown in communication with both sides not really sharing their concerns.

How do you know what to say?

Listening is more important than talking. Ask your loved one what will help them in this situation. If they want to talk, encourage them with questions that help them to explore and make sense of their experience. Help them to think through treatment options, by identifying what is important to them and what they know about the treatment offered. If they do not want to talk, you can show respect by not pushing them to talk and offering practical help instead.

Premature advice

Sometimes we jump in and tell our loved ones not to worry or be positive before we have even found out how they are feeling. This can lead to a shut down in communication.

Negative emotions do not go away just because we ask the patient not to dwell on them. It may be better to acknowledge that they are distressed and show respect for how they are coping.

Using your own experiences or the experiences of others usually does not help. No two people are the same; so even if they have the same illness, their experience and the impact it has on their lives will be different.

Offering Help

Some patients value their independence and it is important to allow them to do as much as they can for themselves.

Even though they may be physically weak, they may still want to be involved in their usual responsibilities.

However it is important to make it clear that you are willing to help and give practical suggestions as to how you can help with:

- Transport to hospital
- Accompanying a patient to a consultation or scan appointment
- Domestic chores
- Supervising children
- Spending time, whether it may just be sitting down, listening or arranging special outings
- Do not forget to talk about other things apart from illness.

Visitors & Visiting

Talk to your loved about their preferences for visitors. They may have good days and bad days and may worry about causing offence if they turn visitors away. You can help able by offering to communicate with visitors.

Remember: Carers need to look after themselves as well

- If you are also the patient's carer, here are some additional tips to bear in mind:
- Inform yourself about your loved one's illness and the emotional impact.
- You may have less time for friends and relatives but it is important to maintain supportive relationships.
- Look after your own health. Eat well, exercise and try not to miss your own doctor's appointments.
- Accept offers of help and try and share the load with others.

THE HUNT FOR IMPROVED PALLIATIVE CARE NATIONWIDE

By **Wendy Loo**, Public Relations Executive, Hospis Malaysia

6th **June 2015** - Some 130 treasure hunters gathered at the open air carpark provided by Bangsar Village, ready for the start of Hospis Malaysia's 14th Charity Treasure Hunt. Held once a year, the Charity Treasure Hunt helps to raise funds for Hospis Malaysia as well as raises awareness on the importance of palliative care in the Malaysian community.

After a breakfast sponsored by Chawan Café, thirty-five teams waited excitedly for the hunt to start, their cars at a ready. One team in particular, from Pestech, the dedicated sponsor for the Charity Hunt for three consecutive years, was raring to go, their eyes set on winning the Grand Prize. After a welcoming speech by the Chairman of Hospis Malaysia, Brig. Gen (Rtd.) Dato' Richard Robless thanking all sponsors and hunters for their support and contribution towards palliative care efforts, the hunt was on. Cryptic messages and questions in hand, the hunters raced around the different parts of the Klang Valley, solving the puzzles and completing the tasks before they ended their hunt at Eastin Hotel.

Once there, the participants of the Charity Treasure Hunt took part in a survey that looked at the public's perceptions about palliative care.

The participants were also introduced to the nationwide advocacy campaign that promoted the symbol for palliative care and what it signified as they waited for the champions to be announced. They also signed a pledge calling for action to improve access to palliative care and ensure minimum standards of care provision across the country. Hospis Malaysia is hoping to reach 15,000 Malaysians to be signatories of the pledge by the end of 2015.

For more information about palliative care and its symbol, please refer to www.palliativecare.my.

To participate in the survey, please refer to www.hospismalaysia.org/events/special-news/275-palliative-care-a-public-survey-by-hospis-malaysia.

THANK YOU!

Hospis Malaysia is grateful to have been elected as a beneficiary of or be a part of the events listed below. In recent years, Hospis Malaysia has taken on a national role, advocating for better access to minimum standards of quality palliative care in the country, and creating greater awareness about this medical sub-specialty. Apart from the clinical services which are offered to our patients free of charge, Hospis Malaysia supports the country in the training and education of healthcare professionals involved in palliative care. Our annual operating expense currently exceeds RM3.5 million and is currently funded entirely from individual and corporate donations. Through being elected as a beneficiary for public events, Hospis Malaysia is able to further spread awareness for palliative care and raise funds to enable us to continue our work.

Colours of Hope 2015, March Jointly organised by the Leo Club of SMK USJ 4 and Leo Club of Sunway Metro (O), the 5K colour run dedicated its efforts on raising awareness for palliative care when the youth organisation learnt the importance of palliative care.

Berjaya Cares Foundation, March Berjaya Cares Foundation has been a regular corporate supporter of Hospis Malaysia. This year their theme: 'Let's Go – Plant a Seed of Love' encourages individuals, especially youth, to volunteer and contribute their time, skills and talent towards a good cause and make a difference within their communities.

International SOS 30th Anniversary, May Hospis Malaysia was the sole beneficiary for International SOS's recent fundraising drive. Some top management and staff went bald alongside other internal fundraising initiatives. The company's senior management reiterated that improving the quality of lives of their clients and quick turnaround of response time were common values they felt International SOS shared with Hospis Malaysia.

The Star's fit for Life, April An event that brought about 40,000 visitors across a three day period. The event helped spread awareness for palliative care and helped to raise funds for Hospis Malaysia and provided a platform to garner for more signatories to Hospis Malaysia's campaign for better access to and improving the standards of palliative care in the country.

Watson's for palliative care Ramadan Special, June Health and beauty retailer Watsons Malaysia joined forces with GSK to raise funds for Hospis Malaysia as part of its 'Watsons for palliative care' initiative. Watsons donated 10 sen for every Panadol or Panaflex purchased at its stores nationwide throughout the Ramadhan period. The Watson's team elected Hospis Malaysia for their commendable efforts to empower the community and improve palliative care services in the country.

Wesley Methodist School Interact & LEO Club, July A big thank you to the two youth community service clubs at Wesley Methodist School for electing Hospis Malaysia as the beneficiary of their fundraising initiatives throughout the year. The school's community service club has elected HM for the second consecutive year and Hospis Malaysia looks forward to their continuous support in the coming years.

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

ASIA PACIFIC HOSPICE CONFERENCE 2015: TRANSFORMING PALLIATIVE CARE

The Asia Pacific Hospice Palliative Care Network (APHN) organises a bi-annual conference as a platform for the various individuals involved in hospice and palliative care to share scientific, evidence based practices and new developments in the field. This year, the Hospice Foundation of Taiwan hosted the 11th Asia Pacific Hospice Conference (APHC) at the Taipei International Convention Centre in Taipei, Taiwan. The three-day conference themed 'Transforming Palliative Care' aimed at reflecting on the numerous changes taking place in the palliative care scene across the region and globally.

"A conference is a time for networking, validation and exploration of what we can do in our own countries for palliative care development and advocacy. We need to maintain high-standards in our services, to practice with rigour and passion. As we see the transformation of palliative care through time, we should cherish the work already done in the area of end of life care and strive towards improved and better care for our patients and their families", says Dr Ghauri Aggarwal, Scientific Chair of the conference.

Pre-conference: Research and Advocacy

Amongst the pre-conference workshops was an Advocacy workshop by Dr. David Praill, former CEO of Hospice UK and Chair of ehospice (UK) and Dr. Steven Connor, Senior Research Fellow of the Worldwide Hospice Palliative Care Alliance (WHPCA) that looked at how to structure an advocacy programme. Professor Margaret O'Connor, emeritus professor of school of nursing and midwifery and Professor Patsy Yates, president of Palliative Care Australia both experienced Australian academics, also provided a useful workshop on conducting research in palliative care. Both workshops had added relevancy for the Hospis Malaysia delegates at this prominent conference as our organisation steps up its focus on advocating for evidence-based quality palliative care. Research continues to build prominence in Hospis Malaysia's work, and the advocacy work we embark on will require solid data to support our calls for change and development.

Scientific Programs and Workshops

"The workshops were a great way to learn - following a series of lectures, we formed small multi-disciplinary groups and practiced applying our newly acquired knowledge and skills on issues and questions derived from our own day-to-day work. The workshops focused on topics such as paediatrics, whole-person care, spirituality, communication skills, teaching and education," reflects a conference delegate, Dr Chi-Li, *Australian based palliative care physician and founder of Palliverse, via ehospice.*

SOME KEY TAKEAWAYS FROM THE CONFERENCE:

1. The Role of Nurses

"Nurses confront suffering routinely", said Joan Ryan, a palliative care clinical nurse consultant (Australia). "They are faced with ethical and moral dilemmas within the context of end-of-life care". As such, nurses are a vital resource when making clinical decisions as they are integral to patient care, and are more able to inform the multidisciplinary palliative care team about the cultural context, moral distress and compassionate care that occurs at a patient's side.

Professor Patsy Yates and Professor Margaret O'Connor looked at the crucial role nurses play in multidisciplinary research efforts in palliative care. Professor Yates showed how nurse-led research reflected a strong interest in understanding patient and carer experiences, improved care outcomes and ensured access to quality palliative care to all, even in harder to reach populations. Professor Margaret O'Connor, on the other hand, talked about the increasing need of nurses to contribute and integrate evidence-based practices in patient-focused activities.

2. Communication is Key

Dr Priyadarshini Kulkarni, Medical Director of Palliative Medicine, Cipla Palliative Care and Training Centre (India) pondered on the difficulty of telling patients the truth about their diagnosis or prognosis. Sensitivity is vital, as telling the truth wrongly can destroy hope and create negative outcomes. Understanding the patients' needs and available support systems, Dr Kulkarni said, is yet another crucial element before healthcare professionals are able to disclose the truth fully to the patient.

3. A Look at Spirituality

Dr. Noreen Chan, Senior Consultant, Dept. of Haematology-Oncology

(Singapore) delivered a thought-provoking lecture on contemporary views on spirituality in the East and West. The need for a distinction between the two perspectives was also questioned. "Spirituality is uniquely individual and deeply personal, and may not involve adherence to a particular faith," she opines. "More importantly, spirituality should be integrated into healthcare systems, and not only in palliative care."

Joan Marston, CEO of the International Children's Palliative Care Network (ICPCN) based in South Africa mentioned that palliative care professionals sometimes found it difficult to understand what children are saying as they use many different verbal and non-verbal ways to communicate with adults. Marston discussed expressions of spirituality in children, and how their carers can connect to the child's expressions whilst assessing and responding appropriately to the child's spiritual concerns.

4. Challenges in Palliative Care

Professor Baroness Ilora Finlay of Landaff, Oncology and Palliative Medicine, Cardiff University (UK) talked about the different challenges faced in palliative care, which ranged from the sensitive topic of euthanasia and physician-assisted death, financial issues in policy making, to providing education and training in skills necessary for palliative care. Professor Baroness Finlay also stressed the importance of clinicians' behaviour. "The doctor's attitude influences the consultation and patients' thinking profoundly. Yet, validity of any decision requires that the patient has accurate unbiased information, the mental capacity to understand fully the implications of the decision and each decision must be free of coercion."

Prof. Baroness Illora Finlay addresses the conference theme in her plenary session

Professor Baroness Finlay also talked about the murky definition of palliative care globally and the need to define it properly. "Palliative care is a recent specialty in some parts of the world; in others, it has been viewed as an area for all health care professionals to become upskilled in care of the dying."

This confusion makes it difficult to radically improve end-of-care life and the quality of life of patients with life-limiting illnesses. To top it off, the criteria as a palliative care specialist differs around the world, with most countries having only ad hoc training programmes, compared to the UK where there is a four-year comprehensive training programme.

In order to gain quality of care, Professor Patsy Yates, together with Dr Rosalie Shaw, the former Executive Director of APHPCN called delegates to set and monitor national standards of care in their respective countries despite the challenges and disparities faced in palliative care services offered in different countries. Professor Yates discussed the need of having the proper systems, structures and resources in place to help support implementation of these national standards, and of identifying areas of improvement through monitoring outcomes of care.

Professor Elizabeth Lobb, who is a professor of Palliative Care in the University of Notre Dame (Australia), highlighted the need to support caregivers to minimise patient and caregiver distress. Skilful care of caregivers requires understanding, she said. Communication between patients and caregivers about end-of-life issues and the caregiver's perceptions of death were discussed.

Dr Stephen Connor's updates conference delegates on the latest advocacy work by the WHPCA in his plenary session

Dr Stephen Connor updated delegates on WHPCA advocacy efforts, such as the recent adoption of a resolution on palliative care by the World Health Assembly, as well as the Global Atlas of Palliative Care at the End of Life, co-published by the World Health Organization (WHO). According to the resolution, palliative care is to be included in all national health policies and budgets, and in healthcare professional education. Furthermore, the resolution emphasises the vital need of countries to ensure adequate supply of key palliative care medicines for pain management in adults and children.

HM hosted a booth at the conference aimed at promoting its annual palliative care-themed workshops and furthering awareness for the palliative care symbol

WORKS OF LOVE: CICELY SAUNDERS AND THE HOSPICE MOVEMENT

By **Professor David Clark**, @dumfriesshire Professor of Medical Sociology and Welcome Trust Investigator, School of Interdisciplinary Studies, University of Glasgow on 14 July 2015, published on openDemocracy.net.

Profoundly rejecting the fatalistic response of the medical establishment, a new movement placed people at the heart of compassionate care at the end of their lives.

One month before the Beatles "All You Need is Love" rocketed to the top of the British pop charts in the summer of 1967, a new institution called St Christopher's Hospice opened in quieter fashion in the London suburb of Sydenham. It was the first of its kind in the world. The founder of the hospice was a pioneering doctor, nurse and social worker called Cicely Saunders, and her new project was also a work of love—though her musical tastes lay more with Ralph Vaughan Williams than Lennon and McCartney.

Saunders was born in 1918 and she died ten years ago today, July 14, at the age of 87. She is widely acknowledged as the founder of the modern hospice movement and a key catalyst in its wider development around the world. Her contribution was to define a new field of care that focussed on the last stages of life, particularly when associated with progressive diseases such as cancer or neurological conditions. This came to be known as "palliative care," an extra layer of support for adults, children, families and communities designed to prevent and relieve pain and suffering when death is impending, and in bereavement.

Though motivated by her Christian beliefs, Saunders harnessed the love of people of other faiths—and none—to a neglected cause. This required challenging the orientation of medicine to death at the time with all its taboos and silences. In their place, she opened up a practical, personal, political and philosophical space for engaging with the care of the dying, and with death itself.

Born into a prosperous family, she enjoyed many of the comforts and the lifestyle of the English upper middle classes. Her father was a land agent and the changes that came in the wake of World War One brought opportunities to profit from the sale and restructuring of estates and farms across the United Kingdom. At boarding school from the age of 14 Saunders was often unhappy, but this experience seems to have fostered in her a belief in the underdog — or as she subsequently said "people who felt shut out."

In her late teens and after some cramming, she gained entry to Oxford University to read Philosophy, Politics and Economics. But when war broke out in 1939 she became increasingly concerned about being sequestered in academic study, so she went to St Thomas' Hospital in London and trained as a nurse. When the war ended she returned to Oxford to graduate and then enrolled as a hospital 'almoner' or medical social worker.

She was now moving in evangelical Christian circles, an orientation from which she retreated in later years even as her faith grew stronger. She once told me that she 'believed less' towards the end of her life, but held these remaining beliefs much more deeply. She also turned her back on the proselytising and restrictions of evangelicalism in favour of a faith that included many perspectives and cultural influences.

In 1947 she met and began caring for David Tasma, a waiter from Poland who had survived the war but was now dying of cancer in the London Hospital. Their conversations were life changing to her, particularly in emphasizing the need for love and understanding for those close to death, and the possibility of developing more suitable environments in which that care could be provided. Paraphrasing the New Testament, Tasma asked Saunders for "what is in your mind and in your heart," which she interpreted as the challenge of combining intellect with compassion.

After his death she set about learning more about caring for people with terminal malignant disease, and by the mid-1950s she had embarked on a third professional training as a doctor. Fuelled by her nursing and social work experience, she was now entirely focussed on an area which interested few others at the time:

improvements in the care of the dying.

Her inspiration came from the handful of religiously-oriented terminal care homes that existed around London at that time. In her final year at medical school she published an article on dying from cancer in the St Thomas's Hospital Gazette. It was both a manifesto and a call to action. Not only did it describe the clinical challenges of such care, but it also set out a plan for how homes for the dying could be developed.

She went to work at St Joseph's Hospice in Hackney, a precursor of Saunders' vision for a new institution that provided a wider range of care and set out to influence the healthcare system through teaching, research and advocacy. Here in London's East End she honed her clinical skills and approaches.

Saunders combined the warmth and solicitude of the hospice with a new realism about the value of narcotic drugs. Pain must never be allowed to gain the upper hand, she felt. It must be prevented as well as relieved. Regular giving was the key. "Constant pain needs constant control" was her mantra—for example through frequent injections of Diamorphine as well as judicious use of the "Brompton Cocktail," an exotic mix of gin, morphine, tincture of cannabis, and cocaine. By such means the easeful death described by nineteenth century forbears such as William Munk could be achieved, but with no deliberate intent to bring about the end of life.

She also listened carefully to patients' stories, learning that their suffering went beyond the physical. When one of them told her that "all of me is wrong," she coined the term "total pain" to include its social, psychological and spiritual dimensions. This required a team effort, bringing together skills from medicine, chaplaincy, social work, nursing, and lay volunteers.

Such was the model for the modern hospice: a place inspired by faith that provided excellent clinical care but also—unlike its predecessors—education, research, policy advocacy and a beacon of inspiration to others. It was to be an independent charity located outside the British National Health Service and a visceral source of opposition to euthanasia, for which support had been growing in Britain since the 1930s.

“She coined the term “total pain” to include its social, psychological and spiritual dimensions. This required a team effort, bringing together skills from medicine, chaplaincy, social work, nursing, and lay volunteers.”

The success of St Christopher's was phenomenal. It became a hot-bed of training for an entire cohort of health professionals who were disillusioned with modern medicine's approach to the dying—rejecting both the fatalism that abandoned those close to death as well as the futility of inappropriate interventions that did more harm than good. In their place, the hospice sought a middle way that combined sound medicine with compassionate care.

St Christopher's became a source of knowledge, good practice and information for people worldwide who sought to tackle the pain of terminal cancer and offer support beyond the medical paradigm. They were concerned, as Saunders put it, "both with persons and as persons." The hospice was widely emulated in Britain, and inspired a different approach in the USA where hospice home care was the prevalent early model, led by a friend and associate of Saunders called Florence Wald, the Dean of Nursing at Yale University.

Engaging directly with the full personhood of both carers and the cared-for meant throwing away the technique of professional distancing from patients that was prevalent at the time, and replacing it with a new and more human form of engagement.

This new approach embraced rather than retreated from the intersubjective experience of care at the end of life, recognising that everyone involved is touched in some way. It privileged the otherwise abandoned and stigmatised dying individual by insisting that "you matter because you are you." Above all, it profoundly rejected the fatalistic response of the medical system when cure is no longer possible and the attitude that 'there is nothing more that we can do.'

In 1987, twenty years after St Christopher's opened its doors, the British medical establishment finally recognised the new field of care that Cicely Saunders had defined. It was called "palliative medicine." The name had been suggested by Canadian surgeon called Balfour Mount who took the St Christopher's model and rolled it out in a large teaching hospital in Montreal. Physicians long familiar with the palliation of symptoms were now offered a whole new approach to medical care in the face of life-limiting illness, and one that was no longer confined to the final stages of life.

Saunders lived long enough to see the fruits of her labours as the hospice movement spread across the world and palliative medicine became officially recognised in many countries' health systems. Her legacy continues to reverberate today, but the challenges are different. For many people, cancer has been transformed into a chronic illness. Longevity increases. And the kind of care supplied by the hospice must be offered to whole populations rather than offering "a bit of heaven for the few" as an associate of hers once put it.

> ***"the kind of care supplied by the hospice must be offered to whole populations rather than offering "a bit of heaven for the few""***

Many of us now face the prospect of a long life that may contain bouts of illness, the possibility of dementia, and the onset of frailty and disability. In this context it is less easy to separate living from dying, so what does that mean for the future of palliative and hospice care? To find the answer to that question we must rekindle the compassion, insight and pragmatism that were so tellingly combined in the life of Cicely Saunders.

OUTPATIENT REHAB SESSIONS AT HOSPIS MALAYSIA: AN UPDATE

by **Wendy Loo**, Public Relations Executive, Hospis Malaysia

Rehabilitation plays a vital role in a patient's life, as it aims at enhancing and restoring functional ability and the quality of life of patients. Many patients develop mobility issues as their illness progresses, and this sometimes Impacts their quality of life. As such, the goals of the outpatient rehab sessions every Tuesday include maintaining, if not improving the patients' physical, social and emotional health.

Raymond Toe, Hospis Malaysia's occupational therapist, attends to the needs of these patients during his home visits as well as during our weekly outpatient rehab sessions. He is assisted by a dedicated team of volunteers, who meet with Raymond beforehand to discuss the progress of the patients, the ways to help the patients gain mobility and functional ability, and on how to coach the patients as they practise their rehab exercises.

Before a patient can join, Raymond needs to assess the patient to ensure that they are able to attend the rehab sessions. Each session generally has about 10 patients, who have been separated according to the severity of their functional disability.

Individual patients exercise with the help of at least two trained volunteers, while more mobile patients participate in group exercises, with several volunteers demonstrating the moves and monitoring the patients. Raymond supervises between the different groups, lending a helping hand where needed – be it just observing the patient, demonstrating a move, showing a volunteer how to support the patient's rehab exercise or training the carers, who also attend these sessions occasionally.

The number of patients attending these sessions is increasing, and it is hoped that this program can be continuously improved.

"Everyone works as a team, and is enthusiastic to help and make these outpatient rehab sessions productive," said Raymond. "We want to increase the patient's confidence, to help maintain or improve their quality of life. Using more fun, therapeutic and interactive activities and exercise programs, we can improve their self-esteem, concentration and emotional levels."

PAST & UPCOMING WORKSHOPS

Palliative Care Nursing
24 – 25 January 2015

Facilitated by Jan Phillips, an Australian Palliative Care Nurse Consultant and educator, the workshop was the perfect forum for palliative care nurses to learn more about the different aspects of taking care of patients and managing their symptoms, particularly in pain. The participants were also given the opportunity to practice symptom management hands-on.

Communication Skills
4 – 5 April 2015

How do you deal with the elephant in the room? How does one impart bad news to patients and their families, or talk about taboo topics such as death? Communication is crucial in any field, at any time, and anywhere. This workshop, which was facilitated by Dr Ednin Hamzah and Dr Sylvia McCarthy, the Medical Director and the Deputy Medical Director of Hospis Malaysia, gave participants some useful tips on communication, and allowed them to practise this core skill.

Hospis Malaysia Foundation Workshop
23 – 26 May 2015

This four day workshop offered clinicians, senior nurses and other allied healthcare providers a general overview of palliative care. Topics covered are clinical assessment, communication skills and clinical management. Facilitated by Dr Ednin Hamzah and Dr Sylvia McCarthy, Teaching is done in small groups with hands-on training, case studies, role plays and patient interactions rather than straightforward didactic lectures.

UPCOMING WORKSHOPS

Training the Teachers for Palliative Care
26 – 31 July 2015

Teaching others is not an easy task, but it is usually a necessary skill for palliative care professionals who may train others. The first workshop of its kind in Malaysia, it will help develop teaching methods for the various healthcare providers involved in palliative care. Dr Ruthmarijke Smeding, one of the best-known researchers in the field of bereavement support, Professor John Ellershaw, the Director of Marie Curie Palliative Care Institute in Liverpool, and Dr Ednin Hamzah, the CEO and Medical Director at Hospis Malaysia, will facilitate this workshop to a limited group of under 20 participants.

Suffering & Hope
21 – 23 August 2015

Suffering and hope – the two sides of the coin of life-limiting illnesses. When curative treatment is futile, how does one give hope? This workshop looks at how healthcare providers can help alleviate some of the suffering patients with life-limiting illnesses and their caregivers go through. Two experts from New Zealand – Dr Sue Marsden and Liese Groot-Alberts – will conduct this meaningful and important workshop for healthcare providers who are involved in making crucial decisions on when to transit to palliation.

Paediatric Palliative Care
25 – 27 September 2015

Palliative care encompasses a whole range of healthcare sectors. Among one of these sectors includes paediatrics, a less well-known area, despite the fact that many children suffer from various limiting illnesses. This workshop not only looks at symptom management and physical distress, but also at the psychological, social and spiritual distress patients and their families may feel due to the illness.

Pain and Symptom Management
7 – 9 November 2015

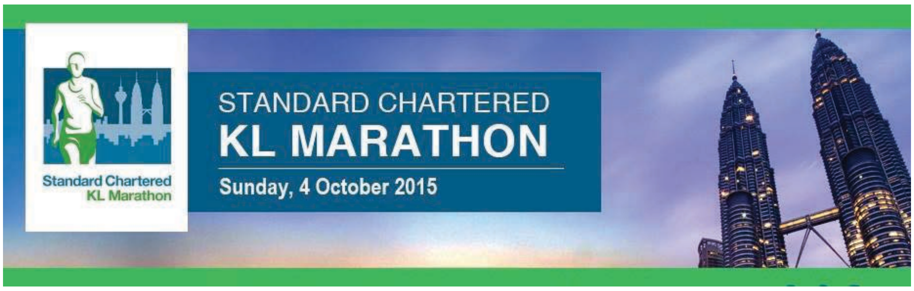
Pain is an inevitable and unavoidable aspect of life. In patients with life-limiting illnesses, it is the aim of palliative care professionals to contain and limit pain both pharmacologically and psychologically so that patients are able to live their lives meaningfully with as little distress as possible, and have improved quality of life.

Grief and Bereavement Care
12 – 13 December 2015

Although many associate grief and bereavement with death and what happens after the death of a loved one, grief and bereavement care starts before death, whilst the patient is receiving treatment. Many patients experience death anxiety, and the stress of cumulative loss. Palliative care aims to support them and their caregivers in this time of need, facilitating the process of adaptation to loss and allowing the patient and their caregivers to go through the process of grief by focusing on end-of-life needs. Renowned leading expert, Professor Amy Chow from the Department of Social Work and Social Administration, in the University of Hong Kong, will facilitate this workshop.

To register for the workshops, please visit www.hospismalaysia.org/events/training-a-education For further information, please email info@hospismalaysia.org or contact Wai Mun at 03 - 9133 3936 (ext: 267)

UPCOMING EVENTS & UPDATES



STANDARD CHARTERED KUALA LUMPUR MARATHON 2015

The Standard Chartered Kuala Lumpur Marathon is set for **Sunday, 4th October 2015**. For the third consecutive year, Hospis Malaysia has been elected as one of the beneficiaries for this unique event, which is a great platform to not only raise the much needed funds, but also to raise awareness about palliative care, and the need to improve access to quality palliative care in the country. Individual runners have signed up to help by participating in the **Run for a Cause** category. Corporations can help by joining the **Corporate Challenge**. Check out *www.kl-marathon.com/charity/corporate-challenge/about* to find out how you can support us at the KL Marathon.

VOICES FOR HOSPICES 2015

Our gala fundraising dinner event is set for **Friday, 16th October 2015 at the Majestic Hotel (KL).** The dinner features a silent auction, raffle draws and a musical performance by the talented singer-songwriter Najwa Mahiaddin. The theme for this year's dinner, **'Celebrating the Gift of Relationships'**, aims to remind us about the strength of familial bonds, and how those affected with a life-limiting illness should not have to go through that journey alone. Proceeds from the charity gala dinner will help Hospis Malaysia to continue to support these individuals, and to help promote palliative care services in the country. To support our fundraising effort through this charity dinner, contact us at pr@hospismalaysia.org or 03-9133 3936 and speak with Carol or Wendy.

HIDDEN LIVES,
HIDDEN PATIENTS
World hospice & palliative care day

HELP US
UNDERSTAND
WHAT YOU THINK

Take part in our online survey!

A PUBLIC SURVEY – YOUR FEEDBACK IS IMPORTANT TO US

"Even though I knew of palliative care and how much it helps improve the patient's and their caregivers' quality of life, the survey questions still took me by surprise and made me think. I never really thought about what might happen if I suffered from a life-limiting disease," shares Loo Li Wen, a survey respondent.

We would like to better understand public perceptions about palliative care. Please check out details on page 4 for more information.

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