

Is Our Healthcare System Supporting The People's Need for "Health" as defined by the WHO?

By Dr Ednin Hamzah, Chief Executive Officer, Hospis Malaysia

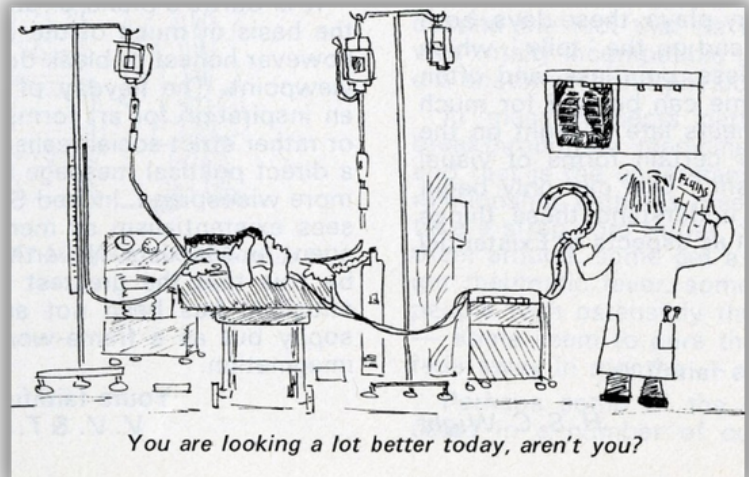
The World Health Organisation defines health as "a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity"

As an individual, we can take measures to manage our own wellbeing such as cultivating a healthy diet, exercising and avoiding unhealthy social practices. But not all illnesses are preventable or can be detected early, and when we do develop illnesses such as cancer, organ failure, we are dependent on getting access to a healthcare system that is able to recognise and meet our needs. And in an ageing society with increasing incidences of non-communicable illness, there is a pressing need for our health service to cater to the needs of such a population.

In the United Kingdom in 2012, a Royal College report that 'NHS patients are suffering poor care in hospitals because they are wrongly viewed by doctors and nurses as simply "medical conditions" to be dealt with rather than individual people'.

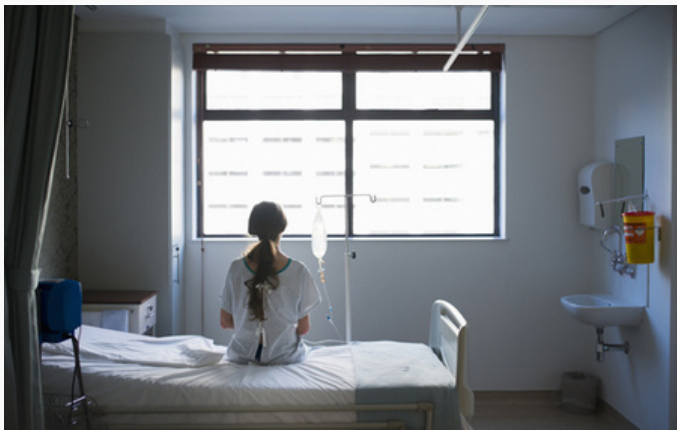
A cancer patient once said of her experience, "the doctors understand cancer, but they don't understand me". This is reflective of doctors who tend to be disease focussed, and therefore tend to only look at the disease outcome such as the patient's kidney function or size of the tumour.

Doctors talk to patients and ask questions to seek information but often do not understand how the illness affects the patient. They may not take the time to differentiate between the severity of a symptom, and how much it bothers the patient. For example, arthritis of the fingers may not be very painful. But because it affects manual dexterity, eating and wearing clothes could be impaired, leading to a loss of independence and dignity. Often, doctors may also flood patients with information using technical language or deliver the information when a patient is in distress and is unable to process the information at that time. Patients need to be respected to be able to participate in decisions that concerns their health and to do so, need information delivered that they can understand. Their priorities usually involve relief of pain and other symptoms, to not suffer unnecessarily or have suffering prolonged. They would want their life to have meaning and to be able to strengthen meaningful relationships as they navigate their illness.



For those with chronic and progressive diseases, these priorities are perhaps more real than just prolonging life. For physicians to truly be able to treat patients, they need to understand both the person and the nature of suffering and know the options available to support their patients.

There are few diseases that medicine cures, the majority are managed to prevent complications and slow progression to maximise quality of life. With increasing burden of diseases especially the non-communicable diseases such as diabetes, cardiovascular, respiratory and degenerative diseases, patients will need lifelong care. Healthcare interventions thus need to meet the patients' goals of care and the various trade offs that treatment options bring. These may include dialysis for renal failure and for cancer, the treatment can often involve a heavy medication load. Some treatments will have significant benefit but others may simply create further burden and suffering for minimal or no improvement in health outcomes. It is not easy for physicians to recognise when a treatment is medically futile. It is equally as challenging to communicate this bad news to the patient and family. There is strong evidence to demonstrate that for physicians to wholly support their patients' health needs, there needs to be a palliative care approach to treating all of them.



Most people would prefer to be cared for and live their final days in the community, yet most are still cared for in hospitals. The Singapore Minister of Health, Ong Ye Kung on 2 June 2022 announced that they hope to reduce the percentage of those dying in hospitals from 61% to 51% in 5 years by boosting support for palliative care in the community and supporting caregivers at home. He told the audience at his ministry's workplan seminar. "I speak from experience. When my mother

passed away, we had a palliative nurse who guided me along the way and really lowered the burden - not just in terms of time spent having to take care of her, but psychologically, what to expect."

It is possible to support patients to be cared for and be supported in managing their illness in the community especially those in life limiting conditions. A good primary care system with basic palliative care, access to essential medicines, a support structure of community care that could also educate caregivers could be set up. This reduces the load in hospitals and could be cost saving as well. Several countries have done so.

Malaysia has all the ingredients to improve the health of our population, especially those with chronic and life limiting disease. But it will require a broad based coalition led by a courageous Ministry of Health that is open to innovative practices and collaborative partnerships.

At a recent regional palliative care conference, a patient stood up and declared,
"Policies are useless unless the benefits are felt by the patient."

And so it should be.

Hospis Malaysia's pillar to drive better access to palliative care

In 1997, Hospis Malaysia conducted its first palliative care lecture for a group of medical undergraduates from University Malaya. This activity has grown over the years to include more students from other universities. Here, Dr. Sylvia McCarthy, the Medical Director of Hospis Malaysia gives us an insight into the other important pillar of the work of Hospis Malaysia – the provision of education and training, including their most recent e-learning.



1 What does palliative care teaching and training in Hospis Malaysia entail?

When we introduce the concept of palliative care, we work to train practitioners to look beyond the diagnosis of a disease and more on understanding the impact of the illness and how that affects the patient physically, psychologically, spiritually and socially. Put simply, we teach the knowledge which is to understand the evidence behind what we do. Then we train the skills required. And this will regularly involve the use of good communication skills. These skills can be applied to enable the practitioner to practise a patient-centred approach to assess a patient, with ongoing two-way discussion between the practitioner and the patient. Then there are skills required to facilitate difficult conversations around what lies ahead, and what to expect as the patient and family journey through the illness.

For post-graduates, the emphasis is firstly on the ability to assess the impact, then to manage this impact. The under-graduates will focus more on communication skills and how to assess if a patient has needs which require palliative care support.

2 What do the lectures and tutorials aim to provide the students with?

We use a blended teaching approach to ensure our training is as comprehensive as possible in the time the student spends with us. There is a combination of lectures, tutorials, more recently e-learning, and attachment to our home visits. This approach aims to improve the students' knowledge and skills, as well as their ethics and attitude, as there is a constant reminder that the focus is on the patient.

3 How does this translate to Hospis Malaysia's vision of providing better access to palliative care to all in need?

There's almost no specialty in which you won't see patients requiring palliative care. To improve access, we need to introduce it to the undergraduates to equip them with the ability to firstly identify a palliative care need when the need arises. Then we need to ensure that doctors have adequate training to be able to practise a palliative care approach to treating their patients when needed. **In other words, not only should they be looking at the disease which most of their training in medical school will involve, but also how the disease affects the patient, and what they can do to reduce this impact.**

4 Do you see synergy between what Hospis Malaysia does in patient care and what it does in its teaching and training activities?

When you teach, you have to be up-to-date. Similarly, a clinical service needs to continuously be updated. And education is one way of keeping ourselves updated.

Also, patients and carers are important members of our teaching faculty. We try and involve them in our teaching as we find they have a lot to teach us and our students. When they share their experiences about their illness and what support they look for when they return into the community, it informs us as to what is needed in a palliative care service, and how we can improve on our delivery.

5 During the pandemic, the Hospis Malaysia team continued with their training and education. Tell us more about it.

At the start of it, we had to suspend our teaching and training. Then we developed the e-learning platform in which students can do it in their own time. This helped us bridge the gap of learning impacted by the pandemic. Our e-learning modules are made up of reading materials, videos and interactive quizzes where students are to respond to problems presented.

6 What are your plans for e-learning at Hospis Malaysia in the near future?

We would like to make our e-learning modules available to any medical school interested in including palliative care teaching in their curriculum.

This may be in Malaysia or across the Asia Pacific region. We are now developing post-graduate modules which can be offered to Family Medicine Specialist trainees, and hope to roll this out soon.

7 What are some of the challenges encountered when you are teaching and training palliative care?

Like all disciplines of medicine, each specialty is jostling for more time in the curriculum. As a relatively new specialty, a longer time for palliative care training would be good as it isn't well understood enough, and as discussed palliative care needs cuts across patients in almost all specialties.

The other issue is a low awareness of palliative care and misperceptions about what it is. Many in the medical fraternity still see it as just basic nursing care or end-of-life care, and this leads to lower prioritization in a medical student's training curriculum.

PLEDGE FOR A BETTER END-OF-LIFE CARE

Are you or someone you know living with a serious, progressive illness such as cancer, organ failure or a degenerative neurological condition such as MND that is causing much physical and/or emotional suffering? If so, read on.

Palliative care considers that death is the natural progression of life, and the journey through life until the end should be given as much respect and dignity as the beginning. Yet many are still experiencing significant suffering resulting from the illness which in medical terms is considered incurable or irreversible. While medical science has its limitations to reversing or curing the illness, there is still much that can be done to ensure that the person behind the illness lives as full a life as possible until the end. Palliative care aims to look at the patient – how the illness is affecting the patient, what is important to the patient at this stage of his/her life, and what can be done to ensure that the patient lives out the remaining time of his life in comfort and with dignity.

In Malaysia, based on a Lancet Commission report on estimating palliative care needs, The Ministry of Health (MOH) in 2019 estimated that more than 220,000 people in the country each year require palliative care as a result of serious health-related suffering*. Currently less than 10% have access to it. The MOH also mapped out the availability of palliative care services in the country*. It identified palliative care services in 7 MOH hospitals located in urban areas while a group of NGO hospices serve the community in similar urban locations, suggesting that such services are currently not available in small towns and rural settings. Moreover, within the 10% who currently have access to palliative care in the country, the majority are patients with cancer. Once again suggesting that despite the availability of the service, the needs of many patients with non-cancer conditions have not been identified, and their suffering not addressed.



PALLIATIVE CARE AWARENESS MONTH *April 2022*

Palliative Care Awareness Month (PCAM) held in April every year, is Hospis Malaysia's initiative in raising public awareness and broadening Malaysians understanding of palliative care, and highlighting the serious gap in access to this crucial healthcare component.



LEAVE NO ONE BEHIND
EQUITY IN ACCESS TO PALLIATIVE CARE

This year's theme "**Leave no one behind - Equity in Access to Palliative Care**", seeks to remind us that it is a basic human right to have access to good healthcare from cradle to grave, and within that, the right to good palliative care as part of the continuum of care. Anyone with a serious, progressive illness regardless of age, gender, race, or social class has the right to care that enables them to live well, free of avoidable suffering and with dignity despite the illness.

* National Palliative Care Policy & Strategic Plan 2019-2030 – Ministry of Health Malaysia

Recently in conjunction with PCAM 2022, some of our caregivers and doctors shared why it is important to make palliative care part of our healthcare system.

" Everyone knows it takes a village to raise a child, but few people realise it takes that same village to support and care for a patient with a life-limiting illness and his/her family. Death and dying is part and parcel of life yet it's still very much a taboo subject that we hardly talk about, let alone plan for in our society.



As a medical oncologist and a palliative care practitioner, I am privileged to be able to journey with my patients with advanced cancer till end of life and experience first-hand, the benefit of early palliative care referral for patients and families.

Every patient and every family is unique and important and it really takes a good team - both professional and lay volunteers in hospitals as well as in the community, to provide holistic patient-centric care that treats patients with life limiting illness as a whole person and supports the families. Palliative care is not just about adding days to life. It is about adding life to days.

Early referral allows us to support patients with life limiting illness and their families to help improve their quality of life right till the end. Much work has been done but more work is needed to build our "village". We need to keep the conversation going, and provide continuous education on palliative care amongst both the medical profession and the public alike.

We need more government and Ministry of Health support for funding, resources, training, and manpower to further develop and expand palliative care coverage across Malaysia to make access to palliative care more accessible and equitable.

My dream is that everyone has that village of support when their time comes."

- Dr Winnie Ling, Medical Oncologist.

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HOSPIS MALAYSIA'S 21st ANNUAL CHARITY TREASURE HUNT 2022 RETURNED WITH A BANG!



After a two year hiatus due to the Covid-19 pandemic, Hospis Malaysia's signature charity event returned in physical form stronger and bigger! This year's treasure hunt which took us from Kuala Lumpur to Penang attracted overwhelming response.

With a long journey ahead, loyal supporters and first-timers arrived excitedly before dawn to get their spot at the front of the line. We were thankful to everyone who were completely compliant to conducting a Covid-19 test ahead of entering the flag-off venue at the carpark of Bangsar Village. And after a final briefing session and a customary group photo, hunters were flagged off at 7.30am sharp by Hospis Malaysia's Council Member, Ms Ho Chee Kit.

Braving a series of accident-related traffic jams along the North-South Highway, the hunters completed their hunt in Icon City, Butterworth, submitting their answers and "treasures" before making their way to Bayview Hotel Georgetown for the evening.



At the prize-presentation dinner on the same evening, huntmaster Liew Kok Seng and his team kept hunters on their toes as answers to each cryptic question unfolded. While the winner struck almost a perfect score and walked away with the top prizes, every team left that evening with a gift.

Hunt-Masters Liew Kok Seng and YS Kong and their team from Euroscale, the mastermind behind every exhilarating hunt for 21 consecutive years, once again performed another challenging yet engaging hunt this year.

HOSPIS MALAYSIA 21st ANNUAL CHARITY TREASURE HUNT 2022



Special thanks to our major cash and grand prize sponsors for making this signature event another great success: Blue Fortress, Lonpac Insurance, LBS Foundation, Dialog Plant Services, Syarikat Ong, KC Chemicals, Great Eastern General (M) Berhad, Rainbow Lighthouse Kindergarten, Symphony Life Sdn Bhd, Crowe Malaysia PLT, Four Seasons Resort Langkawi and Thong Sia Sdn Bhd.

Not forgetting our goody bag sponsors Nestle, Bisou Bites, BOH, AIA, Amoy Canning, Clay Expressions, Aroma Nyonya, Adabi, Vodatel, House of Classic and Biono Enterprise.





Progressing
Palliative Care

PRESENTS

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Ning Baizura

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*Available for donations at RM5,000, RM10,000,
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PALLIATIVE CARE



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13 - 14

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13

**VOICES FOR HOSPICES 2022
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NOVEMBER
12-13

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