

10 YEARS AFTER THE WORLD HEALTH ASSEMBLY PALLIATIVE CARE RESOLUTION –

How has Malaysia fared?

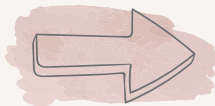
By Dr Ednin Hamzah, Chief Executive Officer,
Hospis Malaysia



In May, 2014 at the 67th World Health Assembly, agenda item 15.5 was a **proposed resolution**: *Strengthening of palliative care as a component of comprehensive care throughout the life course.*

The resolution affirmed that palliative care, when indicated, is fundamental to improving quality of life, well-being, comfort and human dignity for individuals, being an effective person-centred health service, that values patients' need to receive adequate, personally and culturally sensitive information on their health status, and their central role in making decisions about the treatment received.

It also acknowledges that *palliative care is an ethical responsibility of health systems* and is the ethical duty of healthcare professionals to alleviate pain and suffering. It addresses the need for access to essential medicine, education and the inclusion of palliative care as part of universal health coverage.



The adoption of the resolution urges member countries to:

- Develop, strengthen and implement palliative care policies to support the comprehensive strengthening of health systems to integrate evidence based, cost effective and equitable palliative care services in the continuum of care, across all levels, with emphasis on primary care, community and home-based care, and universal coverage schemes.



- Ensure adequate domestic funding and allocation of human resources for palliative care initiatives, including development and implementation of palliative care policies, education and training, and quality improvement initiatives, and supporting the availability and appropriate use of essential medicines, including controlled medicines for symptom management.
- Provide basic support, including through multisectoral partnerships, to families, community volunteers and other individuals acting as caregivers, under the supervision of trained professional.
- Aim to include palliative care as an integral component of the ongoing education and training offered to care providers, in accordance with their roles and responsibilities.
- Assess domestic palliative care needs, including pain management medication requirements, and promote collaborative action to ensure adequate supply of essential medicines.
- Review and revise national and local legislation and policies for controlled medicines, with reference to WHO policy guidance, on improving access to and rational use of pain management medicines in line with United Nations international drug control conventions.
- Update national essential medicine lists in the light of recent additions of sections on pain and palliative care medicines to the WHO Model List of Essential Medicines and the WHO Model List of Essential Medicines for Children.
- Foster partnerships between government and civil society, including patients' organisations, to support the provision of services for patients requiring palliative care.
- Implement and monitor palliative care actions included in WHO's global action plan for the prevention and control of non-communicable diseases 2013 – 2020.



Palliative care was introduced in Malaysia in the 1990s through the efforts of mainly non-government organisations such as Hospis Malaysia and the National Cancer Society of Malaysia. The first Ministry of Health service started in Kota Kinabalu in 1995. In 2019, the Ministry of Health published their National Strategy for Palliative Care 2019 – 2030. Indirectly, the various iterations of the quality of death and dying index (2010, 2014 and 2021) has seen a decline in the ranking of Malaysia compared to other countries.

The recent update by the Department of Statistics Malaysia suggest that *Malaysia will be an ageing nation by 2030 where 15% of the population will be 60 years and over. Ageing communities as well as the rise of non-communicable diseases will create a major need for social and healthcare services with*

palliative care a major need. The notion of a healthy ageing community is a fallacy without a recognition of the need of healthy dying. This normally translates to people wanting pain and symptom relief and a desire to spend their final days at home.

Conforming to many of the recommendations of the WHA 67.19 resolution is not just about health finances but also *reforming health systems, multi-sectoral engagement and collaboration, with an integrative system approach rather than one that exists side by side and are separate, as is currently the case in Malaysia.* Changes in how we work to deliver the services required, will improve both health outcomes and can result in cost savings. There are worthwhile examples in our neighbouring and some low middle income countries.

Malaysia has increased its palliative care services since 2014 but this has mainly been focussed on the introduction of specialist services in hospitals. Thousands of Malaysians need access to palliative care daily. Much of these could be done in the community if there is access to education, training, essential medicines and occasionally emergency services. Patients needs assistance when it is necessary, not if it is provided according to a schedule and where it is convenient for the provider.

At a palliative care conference held in Africa a few years ago, a patient advocate spoke out to policy makers:

“your policies are useless unless the benefit is felt by patients”.

Thus, perhaps when we reflect on whether Malaysia has conformed to the 9 recommendations of the palliative care resolution, think of the lived experiences of members of our community. Did they know they had palliative care needs? Were they able to access medication to relieve their suffering? Were their caregivers supported, such as caregiver training, psycho-social and grief and bereavement support? Were they able to participate in making decisions that involve themselves? If the answer is no, will policy makers care enough to improve it?

Meeting of the WHO Technical Working Group for Palliative Care, Oct 2023, Madrid. As a member of the committee, Dr Ednin has been involved in international palliative care advocacy for over 20 years. The global palliative care community is also evaluating the global progress of palliative care on the 10th anniversary of the WHA 67.19 resolution.



Carving A Career in Palliative Care

Dr Punitha Krishna joined Hospis Malaysia in 2019 with an interest to build a career in community palliative care. Here we asked her to tell us a bit about herself and what inspired her to make the career decisions she has made.



After my housemanship, I spent 4 years in the palliative care unit at Hospital Selayang. I lost both my parents to life-limiting illnesses without palliative care and without clear guidance on how to navigate those difficult moments. When I witness the difference good palliative care support made to those suffering from similar illness and the impact towards patients and family's quality of life and well-being, I decided this was the type of medicine I wanted to practice. I applied for a job to train as palliative care doctor at Hospis Malaysia, and joined in 2019.

Having undergone extensive training at Hospis Malaysia, my work as a palliative care doctor begins each morning leading a team report meeting to ensure every patient receives a thorough assessment and care plan that is evidence-based and patient-centred. I visit patients as needed. I also oversee the working collaboration we have with University Malaya Medical Centre to care for patients with motor neurone disease in the community. Additionally, I am also involved in our teaching programmes, teaching undergraduate medical students and postgraduate family medicine trainees.

Recently, I completed a Master's in Palliative Care at King's College, London as I always wanted to deepen my knowledge and skills but lacked the courage and resources. With support and encouragement from my colleagues and family, I embarked on this journey. The programme offered by Cicely Saunders' Institute within King's College, London consists of 4 modules and a research study project dissertation. I was interested in this programme as it focused on developing skills to appraise research and evidence in palliative care, essential for my clinical practice and service development. The programme's flexibility allowed me to work full-time while studying part-time. The unique modules, such as service development and policy, appealed to me.

Hospis Malaysia emphasizes evidence-based palliative care, integrating best available research with clinical expertise and patient values to promote shared decision making. The programme greatly improved my clinical skills and understanding of research. It is an ongoing learning process and as I grow in the field, my interests evolve. There is much more to achieve, personally and professionally. The programme is just the beginning of my journey.



PHYSIOTHERAPY IN PALLIATIVE CARE - ITS IMPORTANCE AS PART OF THE HOLISTIC APPROACH TO PATIENT CARE

Physiotherapy plays an important role in palliative care to ensure optimum patient care and to reduce the negative effects of serious progressive illnesses. It takes a holistic approach that focuses on the patient's wellbeing in order to improve their quality of life. Here, our *physiotherapist Low Su Jiun* shares her thoughts on physiotherapy in palliative care.

Can you describe your role as part of the clinical team at Hospis Malaysia and why it is important?

Physiotherapy is aimed at improving one's quality of life by preventing complications which may arise from a physical impairment, restoring function, and maintaining one's general well-being. The therapy may be helping with pain management, stretching and strengthening, improving balance and gait pattern, movement retraining, cardiorespiratory rehabilitation, and often, carer training.



Though often overlooked, it is important for the patient to remain functionally mobile which then contributes to the sense of having control over one's outlook, and decision on care direction. Physical limitations can restrict one's activities of daily living. This can then lead to a loss of identity and one's role within a community or family, giving rise to the risk of a negative impact on one's emotional status.

How do you communicate with patients and their families about their physical limitations and goals of care?

Each individual is special, and their functional ability and their needs and goals are different. Together with the clinical team, we focus on early identification of the potential suffering and the patient's needs. Treatment plans are customised based on the patient's goals and we often would like to involve the family and carer for better treatment outcomes.

We will prepare patients and family about potential risks, prevent complication such as pressure sores, contractures, falls and such. At the same time, we guide patients and their family through the inevitable loss of function, negotiate and set realistic goals or offer compensatory strategies when required.



How do you assess patients' functional abilities and mobility in a way that is relevant to their palliative care needs? Can you give us some examples of the kind of therapy you have introduced to help your patients and their caregivers?

The basic functional abilities that are often discussed among patients with palliative care needs focuses on the abilities below:

- Bed mobility such as turning in bed, and ability to get in and out from the bed
- Transferring between bed to chair vice versa
- Sitting and standing balance
- Ability to walk, for instance walking to the toilet and shower room for self-care, walking to the dining and living hall for social activities

For patients who are bedridden, regular turning every 2-hours is essential. Various methods of positioning and the use of air cushion and mattress to alleviate pressure from pressure points will be beneficial. It will be a plus point to perform mobility exercises on or with the patient, which ensures one's comfort, prevent joint contractures and loss of function.

Other than the above, fall prevention is one of the major concerns for many of our patients. The reason being that most patients with palliative care needs might be cachexic, weak, have loss of muscle and these issues can affect their balance. Falls often result in fractures, pain, fear of mobility and developing secondary complications such as pneumonia and physical deconditioning which in turn may hasten the process of deterioration.



Here are some tips to prevent falls:

- > Home environment modification can be useful which include making sure the walkway is free of obstacles and having good lighting around the house.
- > Advisable to use anti-slip floor mat in the showers or toilets. Installation of hand railing and seated showers are recommended. In some cases, indoor shoes with good grip are preferred.
- > Walking aids can be used if required.
- > Lower limb strengthening and balance training will be beneficial.

PAST EVENTS

23RD ANNUAL CHARITY MOTOR TREASURE HUNT
CONCLUDES IN IPOH: 27-28 APRIL



The 23rd Annual Charity Motor Treasure Hunt got off to a thrilling start on 27th April 2024, as participants gathered at the flag-off venue, Bangsar Village. To fuel up for the adventure, teams enjoyed a free flow of coffee from Coffex Coffee and buns from Lavender Bakery and Confectionery.

Despite the early morning start, spirits were high as teams paid attention to the final briefing by Hunt master Liew Kok Seng. After a quick recap of the rules and regulations, teams huddled together for a group photo before embarking on their journey.

The sun was just starting to rise as teams departed from Kuala Lumpur, setting off on their challenging course to the finishing point at Travelodge Ipoh. This year, teams ventured north to Ipoh via the West Coast Expressway (WCE), a new route for both the teams and organizers. The change of pace didn't faze the participants, who were determined to claim top prizes and bragging rights. While some new faces joined in on the fun, familiar teams also made a strong showing, showcasing their expertise and skill, with some emerging victorious in their quest for top prizes.

Our sponsors' support has helped make this event possible and we are grateful for their commitment to Hospis Malaysia.

We are grateful for the generous support from our cash sponsors:

- Blue Fortress Sdn Bhd
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We would also like to express our gratitude to our prize and goody bag sponsors:

- Aeroline First Class Shuttle Sdn Bhd
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- Four Seasons Resort Langkawi
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- Revive
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- Thong Sia Sdn Bhd
- Travelodge Ipoh



The 23rd Annual Charity Motor Treasure Hunt may be over, but we're already looking forward to next year's adventure!

Click [here](#) to see the Treasure Hunt 2024 Photo Album.

A TAPESTRY OF CARE: OPPORTUNITIES IN DEVELOPING PALLIATIVE SERVICES ACROSS MALAYSIA

IDENTIFYING OPPORTUNITIES TO DEVELOP SERVICES IN DIFFERING LANDSCAPES



In April, Hospis Malaysia hosted a webinar to explore the opportunities and challenges in building palliative care services in differing landscapes. *Dr Chai Win Lin, a palliative care physician at Institut Kanser Negara (IKN)*, moderated the discussion along with the *CEO of Hospis Malaysia, Dr Ednin Hamzah*. Dr. Chai opened by defining palliative care and underlining the stark global disparity in access to pain relief and supportive care for seriously ill patients. The webinar then featured insights from four palliative care physicians working in states with high projected needs for palliative care services.



Venturing east to Sarawak, Dr. Sharon Choo has driven pivotal palliative care advancements in Sarawak, overcoming significant geographical challenges. Key initiatives include advocacy with policymakers like the Deputy Premier and the State Health Director and securing support for sustainable funding and essential medications. Since introducing a specialist palliative care unit at Sarawak General Hospital in 2021, patient numbers have doubled. To extend services to rural areas, she launched a domiciliary palliative care project in 2022, which has expanded state-wide. Dr. Choo emphasizes capacity building through collaborations with the American Society of Clinical Oncology and the Asia Pacific Hospice Palliative Care Network, providing crucial training for healthcare workers. Future directions include focusing on research to inform policy and establishing a state task force to develop comprehensive palliative care policies and educational modules, ensuring consistent, high-quality care across Sarawak. She concluded her presentation by stating: “In developing palliative care, you can't run it alone. In order to go far, you need to go together in a team.”



Dr. Look Mei Ling, described Johor as a state with significant unmet palliative care needs. She explained that initially, palliative care was nearly non-existent, with patients with poorly managed symptoms and inadequate end-of-life care. After completing her palliative care training, Dr. Look focused on expanding services in Johor Bahru. She engaged decision-makers to secure resources and policy changes, and emphasized awareness programmes through hospital activities and collaborations with NGOs. Her efforts led to significant growth in palliative care services, including increased awareness and referrals, and the inclusion of non-cancer patients in palliative care services. Future plans include expanding community services, education, and research to further improve palliative care access and quality in Johor.

Moving north to Penang, Dr. Lim Liang Yik presented a region with a pioneering spirit in palliative care development, driven largely by strong community-based NGOs. Penang now has a multi-sectoral approach with contributions from public and private hospitals, NGOs, and universities. Key challenges include a lack of comprehensive data, insufficient training platforms, and limited public awareness. Dr. Lim highlighted the need for a more integrated approach encompassing policy, service delivery, education, and data collection. A crucial challenge is the gap between current services and the estimated patient population requiring palliative care. Educational gaps, particularly in advanced palliative care, further hinder optimal care delivery. To bridge these divides, Dr. Lim and his colleagues established the Persatuan Kerjasama Paliatif Pulau Pinang (PKP3) in 2023. This collaborative body aims to achieve a more unified approach through coordinated research, education, and advocacy efforts.



Finally, Dr. Fazlina Ahmad from Kedah presented a compelling case for a community-based approach. The state's Domiciliary Palliative Care (DPC) program exemplifies this strategy. This program leverages a "shared care" model, where primary and tertiary healthcare facilities collaborate to deliver palliative care directly in patients' homes. This approach is particularly relevant in Kedah, with its growing aging population and a high prevalence of non-communicable diseases driving the demand for palliative care. Dr. Fazlina emphasized the importance of early engagement with primary care physicians, often the first point of contact for patients. Continuous communication and collaboration between healthcare facilities, along with ongoing education to empower primary care champions, are all crucial for the program's success.



The experiences of these four doctors weave a rich tapestry of opportunities and challenges in developing palliative care across Malaysia. Each region faces unique circumstances, highlighting the need for adaptable strategies. However, some common threads emerge. Multi-level engagement, collaboration across healthcare sectors, capacity building through education and training, and a focus on community-based care are all crucial for ensuring equitable access to high-quality palliative care for all Malaysians.

TEACHING & TRAINING

WORKSHOP ON DEVELOPING RESILIENCE IN MANAGING CHALLENGING CLINICAL SITUATION: 29-30 JUNE 2024

This workshop was designed to equip healthcare professionals with skills to navigate complexities of their patients' experiences, by providing a compassionate and empathetic presence. By learning to bear witness to suffering and work towards healing, participants will not only develop coping strategies but also cultivate personal and professional growth.

Facilitators: *Liese Groot-Alberts*, a renowned grief therapist in palliative care (mentored by Dr. Elisabeth Kübler-Ross known for her Five Stages of Grief model theorising that people experience a range of emotions when faced with death or loss), and Hospis Malaysia's *Dr Sylvia McCarthy*.



Participants explored the importance of whole-person care, including self-care strategies to mitigate the risks of overload, compassion fatigue, and burnout. Liese brought a unique approach to discussing sensitive topics like grief and mortality, using poetry and humour to make complex subjects more accessible and relatable.



Setting healthy boundaries is crucial for self-care, Liese emphasised. She encouraged participants to adopt flexible yet firm boundaries that are neither too rigid nor too permissive, which she called "backbone boundaries."

By establishing these boundaries, participants will be better equipped to provide empathetic care while also prioritising their own well-being, and avoiding burnout. Liese reminds us "our work is not about grand gestures or overnight solutions but about small, incremental changes that can have a profound impact on individual lives. We are not superheroes or saviours; we are simply human beings showing up each day, being present, and trying to make a positive difference in the world, one step at a time."

Participants who attended the workshop shared their takeaway:

Keshmeer Kaur, doctor from *Kasih Hospice Foundation* noted that "we are all wounded healers trying to make the world a better place one step at a time. But it is important that we do not bring our own experiences, emotions, and biases to our work. And by acknowledging our own vulnerabilities, we can approach our work with empathy, compassion, and authenticity."

Pritha Nambbiar, pharmacist with *Institut Kanser Negara* shared: "The resilience workshop provided a validating environment for self-reflection, enriching discussions and meaningful connections. I appreciated its fluidity, where it was our shared stories that shaped the depth of the dialogue. Weeks later, I am still having 'aha!' moments as I connect what I learnt to my daily work."



In her closing, Liese reminded that despite best efforts, healthcare professionals are just as human as their patients, that "Despite our imperfections, we are encouraged to approach our work with humility, kindness, and patience, recognizing the value of continuous growth and striving to make a meaningful and positive impact on the lives of our patients and their families."

VOLUNTEERING

WE CAN'T DO IT WITHOUT OUR VOLUNTEERS' HELP!

Palliative care is considered whole-person care. It addresses the well-being of the patient from physical symptom management to psychological and psycho-social issues the patient may be experiencing. To ensure that all aspects of the patient's well-being is addressed, palliative care practitioners also look at how the patient's family is coping with the patient's illness and his care-giving.

Caring for a patient at home can be stressful. For a patient referred to Hospis Malaysia for palliative care support at home, our clinical team will work to manage the patient's symptoms, and address family and caregiver distress. Part of the support provided to family's caring for their loved ones at home is the loan of medical equipment. This helps alleviate the physical and often, financial distress associated with having to source for the equipment on their own. The equipment is maintained, cleaned and stored, ready for the next patient's use regularly. To do this, we require support from able bodied volunteers regularly to help us.



In June, a team of students from the *Rotaract Club of Taylor's Lakeside Campus (RACTLC)* came to our centre in Cheras for a day of community service and teamwork. It was truly a gotong-royong session. They were divided into teams assigned to different storage areas.

In the medical equipment storage rooms, they cleaned, arranged, and set aside equipment for repair to give the space a fresh look. Another team cleaned outdoor fans, glass windows and doors, and drains. Other groups were in charge of updating inventory and tidied the space to make them functional and efficient. With minimal supervision, everyone worked like cogs in a machine to ensure the areas involved were spotless and organised.

Throughout the event, students learned about Hospis Malaysia's mission and services, gaining a deeper understanding of our impact on patients and their families. This experience not only taught them valuable teamwork skills but also instilled a sense of social responsibility and compassion.

Thank You! ROTARACT CLUB OF
TAYLORS' LAKESIDE CAMPUS!



Hospis Malaysia's clean up activity occurs semi-annually. Our next gotong-royong clean-up is scheduled for late December/early January 2025.



Meanwhile, if you are planning a group **Corporate Social Responsibility (CSR)** activity, and would like to support us, please email us at pr@hospismalaysia.org.

We have other group-based volunteer activities which you may be keen to help with!

We would like to extend our heartfelt gratitude to our generous donors from *March to July*, whose contributions have made a significant impact on our mission:



The Melium Group for selecting us as a beneficiary of the group's 35th Anniversary Charity Auction.



CIMB Bank Bhd for raising RM6,888 in under 6 hours during their recent Sports Carnival CSR!



Accenture Solutions Sdn Bhd for their generous in-kind donation of medical equipment.



UPCOMING EVENTS

28-29
SEP

WORKSHOP: CLINICAL ETHICS IN PALLIATIVE CARE

3-5
OCT

KLSCM RACE PACK COLLECTION & EXPO @KLCC CONVENTION CENTRE

5-6
OCT

KLSCM RACE DAY @DATARAN MERDEKA

1 DEC

HOSPIS MALAYSIA CHARITY BAZAAR 2024

14-15
DEC

WORKSHOP: GRIEF & BEREAVEMENT



HOSPIS MALAYSIA

Charity BAZAAR 2024

1 DEC 2024, SUN | 9AM - 4PM

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