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HM Center of Palliative Care
Hospis Malaysia

Berita Hospis

Changing the Narrative on Palliative Care

Over the past few years in Malaysia, there has been several articles in both printed and digital media attempting to explain: 'What is palliative care and the difference between palliative care and hospice?'. The response to these explanations is important in that it may shape clinical practices and affect life changing situations. Hence it is even more important to understand the context and potential outcome of the question and response.

Although there are many attempts to differentiate them, all these terms should be seen as similar care models. Their aims are to improve the quality of life of patients and their families. The practise of hospice or palliative care should very much be seen as the delivery of a service to firstly identify the needs of patients with health-related suffering and then address them.

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Changing the narrative on palliative care

Article by Dr Ednin Hamzah, CEO of Hospis Malaysia

Over the past few years in Malaysia, there has been several articles in both printed and digital media attempting to explain: 'What is palliative care and the difference between palliative care and hospice?'. The response to these explanations is important in that it may shape clinical practices and affect life changing situations. Hence, it is even more important to understand the context and potential outcome of the question and response.

The same words may carry different meanings when used by different people in different context. The term 'hospice' originated from the Latin 'hospes' which meant guest and host. Its modern understanding is derived from the work of Dame Cicely Saunders and is focussed on the delivery of a medical service of symptom control and other measures to support patients and families approaching the end of life. Dame Cicely established St Christopher's Hospice in London to provide hospice care in a home like environment. She introduced the concept of 'total pain' where pain is recognised as a multidimensional issue, and that caring for a person with serious health-related suffering necessarily requires the address of the person's total pain.

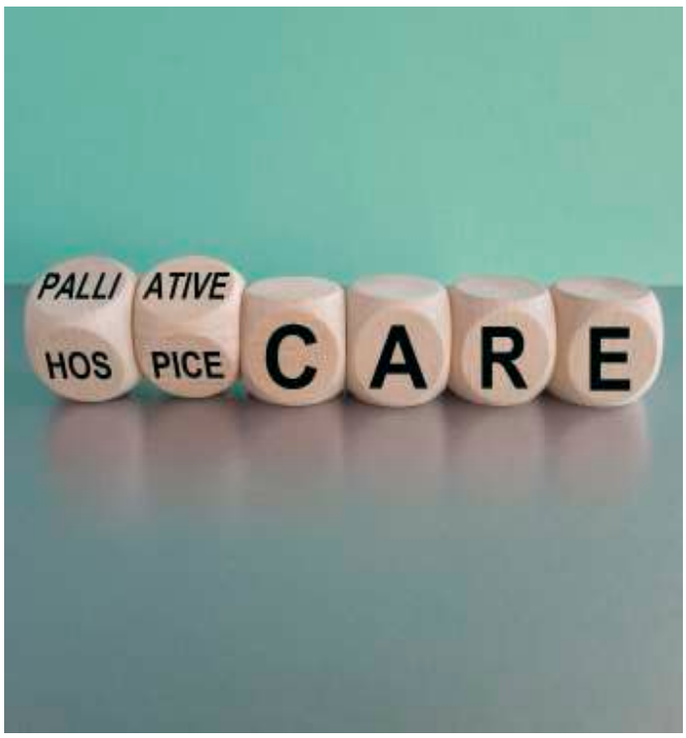
Dr Balfour Mount, who visited St Christopher's Hospice, established a similar unit at the Royal Victoria Hospital in Montreal but opted to use the term 'palliative' — derived from the Latin pallium, meaning 'to cover or cloak' — as the term 'hospice' has a negative connotation in French.

Since then, similar services have been formed across the world that at its core, provide care for patients and families approaching the end of life-although some of the characteristics of such services may vary.

When organisations such as Hospis Malaysia, Hospice Klang, Perak Palliative Care Society and others were formed in the 1990's in Malaysia, their aims were the same, whether they call themselves a hospice or a palliative care organisation as the term is synonymous. The term palliative care is mainly used to describe the approach and specialization process but the core principles remain as that of hospice care.

In later years, the term 'supportive care' became popular as a 'better' way to introduce palliative care into cancer treatment centres, as again some felt the term hospice had negative connotations.

Although there are many attempts to differentiate them, all these terms should be seen as similar care models. Their aim is to improve the quality of life of patients and their families. The practise of hospice or palliative care should very much be seen as the delivery of a service to firstly identify the needs of patients with health-related suffering and then address them.



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Why does this matter in Malaysia? For two reasons. Death is still very much a taboo topic to many in the community and a service that talks about end of life may seem confrontational to those who may not be ready to engage in such potential discussions. Secondly, the improvements in medicine may lead to an over optimistic approach to advanced diseases such that some clinicians feel that recovery may still be possible and hospice or palliative care referral is not necessary. Though there are several screening tools to identify patients with palliative care needs, many physicians insists that such patients are "not ready to be referred".

The University of Edinburgh in 2019 developed an evidence-based tool – SPICT Tool to help clinicians identify the palliative care needs of patients.

Supportive and Palliative Care Indicators Tool (SPICT)

University of St Andrews

NHS SCOTLAND

The SPICT is used to help identify people whose health is deteriorating. Review unmet palliative care needs. Plan current and future care with them.

Look for any general indicators of poor or deteriorating health.

- Urgent or emergency hospital admission(s) or visits.
- Functional ability is poor or deteriorating, with limited reversibility. (eg The person often stays in bed or in a chair for more than half the day.)
- Depends on others more for care due to increasing physical and/or mental health problems. Person's carer needs more help and support.
- Progressive weight loss; remains underweight; low muscle mass.
- Persistent symptoms despite optimal treatment of health condition(s).
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

Look for clinical indicators of life shortening conditions.

Cancer

- Functional ability deteriorating due to progressive cancer.
- Too frail for cancer treatment or treatment is for symptoms.

Dementia or frailty

- Unable to dress, walk or eat without help.
- Eating and drinking less; difficulty with swallowing.
- Urinary and faecal incontinence.
- Not able to communicate by speaking; little social interaction.
- Frequent falls; fractured femur.
- Recurrent febrile illnesses or infections; aspiration pneumonia.

Neurological disease

- Progressive deterioration in physical and/or cognitive function despite optimal therapy.
- Speech problems with increasing difficulty communicating and/or progressive difficulty with swallowing.
- Recurrent aspiration pneumonia; breathless or respiratory failure.
- Ongoing disability with worsening physical and/or mental health after a major stroke or multiple strokes

Heart or vascular disease

- Heart failure or extensive, untreatable coronary artery disease; breathlessness or chest pain at rest or on minimal effort.
- Severe, inoperable peripheral vascular disease.

Respiratory disease

- Severe, long term lung disease; breathlessness at rest or on minimal effort between exacerbations.
- Persistent hypoxia needing long term oxygen therapy.
- Has needed ventilation for respiratory failure or ventilation is contraindicated.

Kidney disease

- Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.
- Kidney failure complicating other life shortening conditions or treatments.
- Stopping or not starting dialysis.

Liver disease

- Cirrhosis with one or more complications in the past year:
  - diuretic resistant ascites
  - hepatic encephalopathy
  - hepatorenal syndrome
  - bacterial peritonitis
  - recurrent variceal bleeds
- Liver transplant is not possible.

Other conditions

- Deteriorating with physical or mental illnesses, multiple conditions and/or complications that are not reversible; best available treatment has poor outcome.

Review current care and care planning.

- Review current treatments and medication; minimise polypharmacy. Shared decision making about treatment and care.
- Review holistic care – symptoms; emotional, social, functional financial, spiritual, cultural needs. Support families and carers.
- Ask for specialist advice or a review if symptoms or other problems are difficult to manage.
- Agree a current and future care plan with the person/family. Discuss future decision making (e.g. Power of Attorney).
- Record, share, and review care plans.

SPICT 2026 - Please register on the SPICT website (www.spict.org.uk) for information and updates.

Early integration of palliative care brings significant benefit to not just patients and families but also utilisation of healthcare systems. Integration into cancer care may also have survivorship benefits.

Despite the calls for early integration of palliative care, the reality is quite different. A paper in 2020 by Jordan R I et al: "Duration of palliative care before death in routine practice: a systematic review and meta-analysis" showed that the median duration of palliative care was 18.9 days before death, weighted by the number of participants. For cancer it was 15 days and 6 days for non-cancer. Thus, in a practical setting, the terms hospice, palliative care or supportive care does not matter as most patients are getting referred late, often at the very end of life. As a result, very little can be done to improve their quality of life, and all that can potentially be done is to honour their preferred place of death.

For many in the public, the terms hospice and palliative care conjure up issues not just surrounding end of life but also a perception of "giving up" as treatment for the disease is no longer possible. However, early referral to palliative and hospice care has demonstrated remarkable improvement in end-of-life outcomes as explained by Tai-Chung Lam et al in 2021: "Integrative Palliative Care Service Model Improved End-of-Life Care and Overall Survival of Advanced Cancer Patients in Hong Kong: A Review of Ten-Year Territory-Wide Cohort."

Hospis Malaysia has found some success in connecting with some clinicians in specialties such as neurology and geriatrics where patients are referred and jointly managed with community palliative care services at an earlier stage of illness.

So perhaps in Malaysia, one should look at responding to the question 'what is the difference between hospice, palliative care and supportive care' by asking 'how is your illness affecting you and what solutions do you hope for?' and the conversation begins…

To support greater public awareness, Hospis Malaysia recently introduced "Center of Palliative Care" as part of its new visual identity to help the public better understand that hospice and palliative care refer to the same philosophy of care. Although some healthcare systems distinguish between the two terms based on specific eligibility criteria and models of care, they are used interchangeably in Malaysia and many other parts of the world.

Advancing Quality Palliative Care: National Standards for Palliative Care Implementation Pilot Workshop

On 17 July 2026, approximately 30 healthcare professionals and stakeholders from hospitals and non-governmental organisation (NGO) hospices across Malaysia gathered for Part 1 of the National Standards for Palliative Care Implementation Pilot Workshop. The full-day session marked an important step towards strengthening the implementation of quality palliative care standards nationwide, with six institutions agreeing to participate in the pilot programme.

The session provided a platform for participants to review the National Standards for Palliative Care Implementation Guide, discuss proposed indicators, and explore the practical considerations involved in applying the standards across different care settings. Through open discussion sessions, participants shared valuable insights from their respective clinical environments, highlighting both opportunities and challenges in translating national standards into practice.

A key focus of the workshop was ensuring that the proposed indicators are practical, measurable, and relevant across various healthcare settings. Facilitators emphasised that the first phase of the pilot is focused on testing the feasibility of data collection using the provided workbook, rather than assessing organisational performance. Participants were encouraged to document implementation challenges and mitigation strategies, as these insights will help strengthen the practicality and applicability of the standards.

The findings from this phase will be reviewed during the subsequent workshop, where participants will analyse the collected data, discuss implementation experiences, and identify areas for further refinement.

Key areas discussed included medication governance and access, caregiver documentation, grief and bereavement support, volunteer management, palliative care training requirements, patient and family experience measures, and documentation of patients' care goals and preferences.

The workshop reinforced that implementing national standards is a collaborative learning process. By bringing together healthcare providers from diverse settings, the pilot aims to develop a framework that is evidence-based, practical, and sustainable for wider adoption.

This workshop is a culmination of several years of drafting the National Standards for Palliative Care and Implementation Guide ("The Standards Guidelines") by a dedicated team of practitioners.

Hospis Malaysia's senior palliative care practitioner, Dr Sylvia McCarthy was a key member of the drafting committee.

As The Standards Guidelines moves into its implementation stage, a working group has been appointed by the Ministry of Health to steer services through its implementation.

Strengthening Access to Medicines Through Partnership with BIG CARING Group

For patients and families navigating serious illnesses, timely access to essential medications can make a meaningful difference in their care journey. Recognising the challenges faced by those receiving care at home, Hospis Malaysia and BIG CARING Group came together in May 2026 to strengthen community-based support through a Memorandum of Understanding (MoU).

Through this collaboration, selected BIG Pharmacy and CARiNG Pharmacy outlets will support the fulfilment of prescribed medications for patients referred by Hospis Malaysia, making it more convenient for individuals and families to obtain the medicines they need while managing care at home.

For many patients receiving palliative care, medications play an important role in managing symptoms, enhancing comfort, and maintaining quality of life. By bringing healthcare support closer to the community, this partnership helps strengthen continuity of care beyond clinical settings while reducing some of the practical challenges faced by families and caregivers.

The partnership reflects a shared commitment between Hospis Malaysia and BIG CARING Group to build a more accessible, compassionate, and person-centred healthcare ecosystem. Through collaboration across sectors, we hope to create stronger support networks that enable patients to receive the right care at the right time, wherever they are.

Hospis Malaysia extends its sincere appreciation to BIG CARING Group for their commitment towards advancing community healthcare and supporting individuals and families navigating their palliative care journey.

"This collaboration between Hospis Malaysia and BIG CARING Group marks a significant step in strengthening community-based palliative care and improving access to essential medications for patients with serious illnesses. Through this partnership, we aim to ease the burden on patients and caregivers by enabling more timely and convenient access to treatment, while enhancing continuity of care at home.

Dr Lim Zee Nee
Medical Director of Hospis Malaysia

"Community pharmacies are among the most accessible healthcare touchpoints in the community and we believe they can play a stronger role in improving access to medication for patients receiving palliative care. Through this collaboration with Hospis Malaysia, we are confident we can progressively help bridge gaps in access to essential medications for more families navigating palliative care over time."

Wong Siew Lai
Chief Marketing Officer of BIG CARING Group

Treasure Hunt Marks Silver Anniversary in Taiping

As Hospis Malaysia celebrated the Silver Anniversary of our Annual Charity Motor Treasure Hunt, it was only fitting that our 25th edition brought participants to Perak, known as Malaysia's Silver State. With Taiping serving as the event's finish point for the first time, its lush greenery, and timeless charm provided the perfect backdrop for this milestone celebration.

After a day of adventure, riddles, and discovery on the journey that began at Bangsar Village, Kuala Lumpur, participants gathered at Novotel Taiping for an evening of celebration and camaraderie.

One of the evening's highlights was the much-anticipated reveal of the treasure hunt answers, sparking laughter, surprise, and plenty of "aha!" moments as teams reflected on the challenges they encountered along the way. Congratulations to our winning teams, whose teamwork, creativity, and determination earned them top honours. Many of our top-performing teams were returning participants, demonstrating that experience, perseverance, and a keen eye for clues truly make a difference.

We extend our heartfelt appreciation to our sponsors, whose generous support helped make this milestone event possible:

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- NOVOTEL TAIPING
- RAINBOW LIGHTHOUSE KINDERGARTEN
- SEIKO
- STARBUCKS
- YTL HOTELS SDN BHD

A special thank you also to our hunt masters, **Liew Kok Seng and YS Khong** (and his team at UpAnte), for helping make this Silver Anniversary edition such a memorable success.

View the 2026 Treasure Hunt Photo Album

Inspiring Future Nursing Leaders Through Community Palliative Care Learning

In April 2026, Hospis Malaysia welcomed a group of nurse leaders from Hong Kong Metropolitan University (HKMU) as part of a learning exchange focused on strengthening understanding of community-based palliative care.

The visit brought together 25 students from HKMU's Master of Nursing with specialisation in Executive Administration programme. Through this collaboration, participants gained insights into the principles and practices of palliative care beyond the hospital setting, with a focus on delivering compassionate, person-centred support within the community.

The learning experience included interactive workshops and home visits, providing participants with an opportunity to observe how palliative care is delivered in real-life settings. A patient and caregiver also took part in one of the sessions, sharing their personal experiences and perspectives. Their stories offered a valuable reminder of the importance of seeing care through the eyes of those receiving it and their families.

Rather than offering a one-size-fits-all approach to healthcare transformation, Hospis Malaysia's goal was to encourage reflection, spark new ideas, and empower participants to explore meaningful improvements within their own healthcare environments. We hope each participant returns with practical insights that can be adapted to strengthen palliative care in their respective settings.

Hospis Malaysia extends its sincere appreciation to Dr Pin Pin Sandy Choi, Dr Sarah Wong, and Dr Yun Wah Lam from the School of Nursing and Health Sciences, HKMU, for initiating this meaningful collaboration and creating opportunities for knowledge exchange across borders.

As nurses remain among the most trusted and consistent sources of support for patients and families, Hospis Malaysia continues to champion their role in advancing palliative care and driving positive change within communities.

Here's what one of the students, Xiong Ye shared about her experience during the learning exchange.

"During the home visits, what stood out to me was the level of respect and professionalism shown throughout the process. The nurse demonstrated excellent communication skills — engaging both the patient and family, conducting assessments, and addressing concerns with empathy and clarity. Through this, we saw how trust is built.

We also observed strong collaboration between nurses and doctors. When needed, the nurse would consult the doctor promptly, ensuring that patients received timely and appropriate care."

A Life in Care : Up Close with Dr Sylvia McCarthy

The people, places and quiet lessons behind more than two decades at Hospis Malaysia

Dr Sylvia as she is fondly known, recently retired as Hospis Malaysia's Senior Palliative Care Practitioner after more than 20 years of service, during which she contributed extensively to clinical practice, education, and national and regional palliative care development. Although retired from her clinical role at Hospis Malaysia, Dr McCarthy remains actively involved in strengthening palliative care. She continues to support education and capacity building through the Asia Pacific Hospice Palliative Care Network (APHN), including initiatives in Timor-Leste, and serves on the committee leading the development and implementation of Malaysia's National Standards for Palliative Care – ensuring access to consistent, high-quality palliative care for all.

For more than two decades, Dr Sylvia has been a familiar and deeply respected presence at Hospis Malaysia. An experienced palliative care practitioner who has contributed to training and education and sector-development initiatives at the national level, she has helped shape not only how care is delivered, but also how generations of healthcare professionals understand what it means to care well.

Yet when asked whether she ever imagined staying at Hospis Malaysia for so long, her answer is characteristically direct: "Definitely not."

There was no grand plan. After ten years in family medicine at Universiti Malaya (UM), Dr Sylvia was ready for a break and hoped to spend more time with her young children. She already knew of Hospis Malaysia through patients she had referred and through Hospis Malaysia's CEO, Dr Ednin Hamzah, who taught medical students at UM. Thinking she might volunteer, she asked whether her help would be useful. The response was immediate: when could she start?

She joined Hospis Malaysia in September 2003, not as a volunteer as she initially imagined, but as a full-time doctor.

A natural path towards palliative care

As a young house officer in the 1980s, she cared for patients living with cancer and people experiencing severe breathlessness or pain from advanced illnesses. Medicine was often focused on treating disease, while young doctors were left trying to support patients through frightening symptoms and deep vulnerability. At the time, there was far less understanding of how those symptoms could be relieved.

Family medicine had already taught her that a diagnosis alone is never enough. A doctor must understand the person, the family and the social circumstances surrounding an illness. A brilliant treatment plan has little value if a patient does not understand it, cannot access it or cannot realistically follow it. Palliative care brought all those elements together.

The privilege of entering someone's home

When Dr Sylvia first joined Hospis Malaysia, the organisation was much smaller. There were only a handful of nurses, limited space and no in-house pharmacy. Workshops took place in the day-care room, while a volunteer pharmacist helped support the clinical team.

Yet the work itself felt familiar. Home visits brought her back to the kind of relationship-based medicine she had practised as a general practitioner in the United Kingdom.

"It is an extraordinary privilege to be allowed into someone's home – to understand their circumstances and to try to make a difference within them."

She remembers accompanying nurses who would arrive at homes where patients were uncomfortable and caregivers felt completely lost. With patience and skill, the nurses would clean and reposition patients, attend to wounds and teach family members how to continue the care. Watching them work revealed, in the clearest way, the power of excellent nursing.

Those early experiences helped establish a principle that would remain central throughout her career: every patient deserves the best care the team can provide.

Dr Sylvia with a patient *(photo credit : SC Shekar)*

Every corner of Kuala Lumpur holds a memory

After caring for thousands of patients, Dr Sylvia finds it impossible to identify only one who has stayed with her. Instead, Kuala Lumpur itself has become a map of memories.

"As you drive around Kuala Lumpur, you think, 'Ah, I've been there,' and something immediately comes to mind about the person you met," she says. "Almost every corner of Kuala Lumpur has a home that touched me."

She hopes she made a difference to the lives of those patients and families. At the same time, she is equally aware of what they gave her: lessons about symptom management, family relationships, coping, healthcare systems and life itself.

"It is very difficult to do this work without it affecting your outlook," she says. "You learn something about life from patients and families."

Curiosity, kindness – and chocolate cake

When speaking about leadership, Dr Sylvia describes herself as "one piece of the jigsaw" and takes pride in leaving behind a strong, compassionate team capable of continuing without her.

The qualities she hopes to pass on are simple but demanding: curiosity, kindness and the aspiration to do more.

Kindness, she stresses, is not the same as niceness. Kindness sometimes requires difficult decisions. A difficult decision to share bad news may sometimes be the best way to help a patient and family navigate their journey through a serious and life-limiting illness. Curiosity prevents healthcare professionals from becoming complacent and assuming that the way something has always been done is the way it must continue.

And resilience? That requires self-awareness: knowing one's capacity, recognising personal triggers, understanding boundaries and knowing when to step back – or when something must change.

Humour matters too. Serious matters must be treated seriously, Dr Sylvia says, but not everything has to feel solemn all the time. "And then there is chocolate cake," she adds with a smile.

Home is people

Beyond medicine, Dr Sylvia is making more time for the interests that have always been part of her life: reading, sewing, cooking, baking, visiting art exhibitions, travelling, and spending time with family and friends.

Having built her life in Malaysia while retaining close connections with families and friends around the world, her definition of home is not geographical.

"Home is not a country. Home is not necessarily a place; it is people – your family and friends."

Asked to describe more than two decades at Hospis Malaysia in three words, she laughs at the impossible task, before adding that Hospis Malaysia has turned her grey!

Behind the humour is a legacy grounded in integrity, persistence and ethical care. Dr Sylvia hopes her team at Hospis Malaysia feels that they work in an organisation where patients remain at the centre – even as policies, procedures and systems grow around them.

And perhaps that is the clearest reflection of who Dr Sylvia is: a doctor whose work has always been closely aligned with the person she is, and whose influence lives on through the people, teams and values she has helped nurture.

Public Education Talks and Advocacy Engagement

Roentgen Run x Komuniti Khidmat Siswa 2026

Hospis Malaysia was proud to partner with the Roentgen Run x Komuniti Khidmat Siswa 2026, organised by the Diagnostic Imaging and Radiotherapy Programme, Faculty of Health Sciences, Universiti Kebangsaan Malaysia (UKM), Kuala Lumpur campus.

Held in conjunction with National Cancer Survivors Day on 7th June, the event promoted healthy living while raising awareness about cancer and the role of radiation in healthcare. Hospis Malaysia hosted an awareness booth to educate participants about palliative care and the support available to people living with serious illnesses, including cancer, organ failure, dementia, and Motor Neurone Disease. Visitors also enjoyed our popular Spin the Wheel of Palliative Care game and took home exciting sponsored prizes.

Integrating Palliative Care into the Eldercare Ecosystem

Hospis Malaysia was honoured to participate in TIME dotCom's Game of Life employee engagement talk series on 25 May 2026.

During the session, Tham Su Ming, Director of Advocacy and Strategy, presented on Integrating Palliative Care Support into the Eldercare Ecosystem, highlighting the growing importance of palliative care in an ageing society and the challenges faced by the sandwich generation balancing multiple caregiving responsibilities.

The session encouraged meaningful discussions on current and future care needs, preparedness, and the role of compassion in supporting individuals and families living with serious illness. We thank TIME dotCom and its employees for the thoughtful engagement and valuable conversations.

Inspiring the Next Generation of Changemakers

At the Service & Sustainability (S&S) KL Youth Summit on 18 April 2026, hosted by the International School of Kuala Lumpur, Hospis Malaysia had the opportunity to engage with students passionate about creating positive change in their communities.

Representing Hospis Malaysia, Subashini Rajasekaran from the Advocacy & Communications team facilitated an interactive workshop exploring the connections between palliative care, service learning, and sustainability.

Through collaborative discussions and real-life examples, students examined how compassion, empathy, and community partnerships can drive meaningful action. The workshop encouraged participants to think critically and develop practical solutions for their schools and communities.

Merdeka with Dignity – Give the Gift of Comfort, Dignity and Independence

As Malaysians celebrate the spirit of Merdeka this August, many of us cherish the freedom to gather with loved ones, share a meal, and create lasting memories. For someone living with a serious illness, however, freedom can mean something far simpler yet profoundly meaningful — the ability to remain at home, have their pain relieved, and spend precious moments with the people they love.

This Merdeka, you can help make that possible.

Through Merdeka with Dignity, Hospis Malaysia invites you to give the gift of comfort, dignity, and compassionate care to patients facing life-limiting illnesses.

At any one time, Hospis Malaysia cares for approximately 400 patients. Every contribution helps our multidisciplinary team provide professional palliative care in the comfort of home, including regular home visits, essential medicines and medical supplies, the loan of medical equipment, and access to our 24-hour emergency call service.

Your support will allow us to reach more patients and families, enabling them to live each day with the best possible quality of life. Make every moment count. Donate today.

HM Center of Palliative Care
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