

# Building Communities. Supporting People.



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## A word from Dr Ednin Hamzah CEO, Hospis Malaysia

“Time and health are two precious assets that we don’t recognise and appreciate until they have been depleted” – Denis Waitley



Palliative care was introduced to Malaysia in the early 1990s with services developing in the community and in hospitals across the country over the years. In 2016, Hospis Malaysia published a needs analysis for palliative care and concluded that only about 10% of those who require it are receiving it. We had also shown that given the choice, most people would prefer to live their remaining days at home.

Modern medicine despite all its innovations and new medicines is unable to cure all diseases. Whilst diseases such as cancer, organ failures and degenerative conditions such as dementia continue to affect many, the Covid-19 pandemic brought unprecedented disruptions to health systems across the globe. Such disruptions in turn led to patients with other diseases unable to seek timely medical attention, resulting in increased suffering. While we may have seen the worst of the pandemic, we are still picking up the pieces on its full impact on our population's general state of health, and its toll on our health system in years to come.

Data tell us that the number of Malaysians requiring palliative care will increase, with unmet needs growing as services are unable to keep up with demand as our population ages. At the same time, we also need to provide some minimum standards to the quality of care, and what the population really needs. Healthcare often seems important only when it is needed and especially with regards to services in the community. The very ill, physically challenged and socially disadvantaged have significant challenges in accessing hospital-based healthcare. These are the very people that require assistance. Hospis Malaysia from its early days recognised this, and has developed its patient services to enable it to be delivered in the community, where its patients are. As was the case during the pandemic, it helped alleviate the patient load in hospitals. Over the years, it continues to advocate strongly for this.

Our palliative care services continue to develop as the need in the community remains high. The key has been collaboration and innovation through increasing knowledge, skills and efficiency and technology. Our web-based electronic patient records allow better understanding and monitoring of our patients' needs whilst improving our capacity of auditing clinical practice.

Through our extensive global network of palliative care collaborations, we have been able to share best practices even during the Covid-19 pandemic and thus continue to work uninterrupted during the challenging times. We are grateful that permission was granted from the Ministry of Health to maintain our community palliative care services as movement restrictions could have limited our clinical team's ability to reach their patients. When physical teaching was not possible, we moved quickly to provide e-learning possibilities for various undergraduate teaching to our various university partners.

Hospis Malaysia participated in the drafting of the Ministry of Health's "National Palliative Care Strategy" in 2019 and hopes that further collaboration with the Ministry of Health will result in better access and quality of palliative care nationally. In line with our vision to improve access, we are striving to support our country's need to recognise that palliative care should be enshrined as part of our commitment to "Universal Health Care".

Those requiring palliative care need voices to speak up so that their concerns are heard and attended to. Public advocacy is needed and our "Speak Up" campaign at KLCC made this a very visual affair graced by government ministers and launched during the "World Cancer Congress" in 2018.

Hospis Malaysia will continue to strive to provide the best care possible with the resources we have. We are a strong voice nationally and globally. We have been featured as a model of care in the WHO Global Atlas of Palliative Care, and have been invited to share our views on the world stage with the WHO Director General.

We hope that when any of us will require palliative care in the future, it will be there for us.

For as  
Nelson Mandela  
once said - "A nation  
should not be judged by  
how it treats its highest  
citizens, but its  
lowest ones."



## The Ethos Of The Organisation And The People Who Govern it

Behind every patient with a serious illness whose life is made more comfortable with pain and symptoms better managed is dedication and commitment from everyone in Hospis Malaysia in their respective roles. From the clinical team and patient services supporting their work to the public advocacy and fund-raising team and the team in finance and operations, compassion, purpose and commitment runs through the veins of the organisation.

Its people are guided with a vision to provide access to the highest possible quality of evidenced-based palliative care to everyone in need to relieve them from, and prevent pain and suffering associated with progressive life-limiting illnesses.

As an organisation incorporated as a company limited by guarantee and registered with Suruhanjaya Syarikat Malaysia (formerly known as the Registrar of Companies), it is governed by its Articles of Association. It is also a tax-exempted organisation approved by Lembaga Hasil Dalam Negara (LHDN), the inland revenue authority of Malaysia. As a healthcare service provider, it is also registered with the Ministry of Health and is governed by the Private Healthcare Services and Facilities Act 1998.

In keeping this together and ensuring its sustainability, it is important that accountability and transparency remains a key guiding principle in all that its people do. And this is the role of the Governing Council which comprises a group of professionals with diverse skills volunteering their time to govern the organisation and provide support to the CEO and his team to steer the organisation forward in years to come.



### Governing Council Members with CEO

*From left to right: Ms Ho Chee Kit, Dr Chong Su-Lin (Secretary), Dato Kathleen Chew Wai Lin (Chairman), Dr Ednin Hamzah (CEO), Ms Lim Wai Yee, Prof Dr Khoo Ee Ming, Dr Ong Hock Chye (Treasurer)*







# Progressing palliative care

In 2014, almost 50 years after the first modern hospice was founded in the United Kingdom, the World Health Assembly (WHA) approved the Resolution - “Strengthening of palliative care as a component of comprehensive care throughout the life course (WHA67.19)”, urging national governments to carry out key actions to develop palliative care globally.

WHA67.19 called for action to be taken on the avoidable suffering of millions of people and their families, and the need to create or strengthen health systems that include palliative care as an integral component of treatment.

In Malaysia, Hospis Malaysia has taken an active role in continuously progressing the provision of palliative care in the country and improving its access in the community.

Whether it is through its patient services, education and training, or engagement with the public as well as government and policy makers, every effort made is driven by a vision to make palliative care an integral part of the nation’s healthcare system.



## The Past 5 Years At A Glance: 2017-2021

In the 5 years from 2017 to 2021, which includes almost 2 years of extreme uncertainty amidst a global pandemic, Hospis Malaysia continued its work in progressing palliative care in the country and the region. During this period, even under challenging circumstances, our people continued to innovate to maintain our work in the organisation's 3 key pillars – patient services, education & training, and public education & stakeholder engagement.

### 2017

#### • APRIL

##### “Pain & Suffering – Whose Responsibility is It?”

Organised by Hospis Malaysia and supported by YTL Foundation, this 2<sup>nd</sup> public lecture was given by Professor Wee Bee Leng, National Clinical Director for End-Of-Life Care, NHS England.



#### • JUNE

##### Sponsorship agreement with Yayasan Sime Darby signed.

YAYASAN

Funding of RM1 million to support the salary of 6 palliative care nurses.



#### • JULY

##### Symposium on Standards organised by Hospis Malaysia in partnership with the WHPCA

A forum that brought together palliative care leaders from across the world to discuss the importance of standards and care indicators in palliative care and its relevance in countries with different resources.

#### • OCTOBER

##### “I Wish I Had Cancer”

Premiered at the Voices for Hospices Gala Dinner, this is the 2<sup>nd</sup> advocacy film by Hospis Malaysia.



#### • NOVEMBER

##### Hospis Malaysia partners with Fusionex

A collaboration to help improve its quality of care through analytics support on patient data.



## 2018

### • OCTOBER

#### Hospis Malaysia at the World Cancer Congress

Hospis Malaysia represented the palliative care fraternity in various discussion forums - “Maximising Quality of Life and Death and Empowering Patients and Caregivers”, “Communicating Future Care Plans with Cancer Patients in Malaysia”.



#### The launch of “Speak Up” – There’s an Elephant in the Room

To celebrate World Hospice and Palliative Care Day, the “Speak Up” campaign kicked off with 10 life-sized elephants on display in front of the iconic Petronas Twin Towers. Taglined “Let’s Start Conversations that Matter”, it was launched by YB Hannah Yeoh, Deputy Minister of Women, Family and Community Development to give a voice to all in need of palliative care.



## 2019

### • APRIL

#### “Speak up” for the 3<sup>rd</sup> Palliative Care Awareness Month

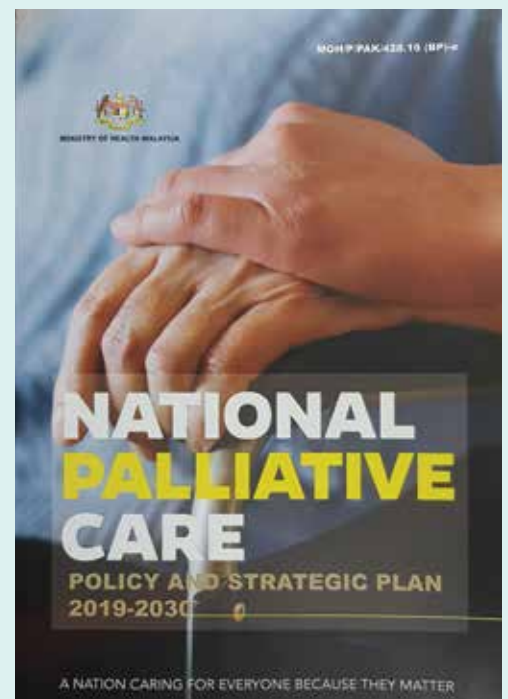
Incorporating the “Speak Up” movement into the global palliative care theme of “Because I Matter”, this month-long campaign was launched at Suria KLCC by the Deputy Minister of Health, YB Dr Lee Boon Chye. It featured a photography exhibition accompanied by stories of patients receiving palliative care support.



### • OCTOBER

#### Towards better palliative care at “Voices for Hospices”

The Minister of Health, YB Datuk Seri Dr Dzulkefly Ahmad spoke at Hospis Malaysia’s biennial Gala Dinner, publicly acknowledging the World Health Assembly Resolution in 2014 which called on the strengthening of palliative care as a component of comprehensive care throughout the life course.



### • NOVEMBER

#### The launch of the National Palliative Care Policy and Strategic Plan 2019-2030 by The Ministry of Health Malaysia (MOH).

A culmination of several years of discussion and planning involving doctors from Hospis Malaysia in key strategic committees such as community, standards, education and training.



## 2020

### • JANUARY

Migration to Microsoft 365 completed.

As part of Hospis Malaysia's ongoing digital developmental plan, this shift provided an upgraded platform which also enabled staff to work remotely when required.



### • MARCH

Lockdown MCO 1.0 began

Clinical team maintained its service amidst the Covid-19 pandemic health crisis and a full movement control order in the country.

### • APRIL

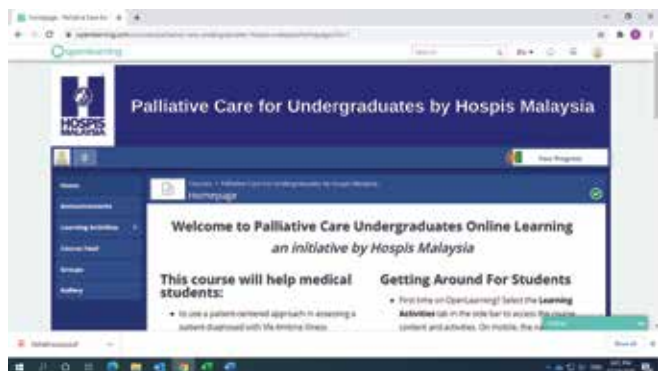
Palliative Care Awareness Month went digital

Hospis Malaysia's annual campaign to increase public awareness continued online despite the pandemic.



Online fund-raising debuted

The collaboration with Lazada, the e-commerce platform, marked the start of a major drive to further digitalise Hospis Malaysia's online fund-raising initiatives.



### • SEPTEMBER

e-Learning commenced

To bridge the gap of learning impacted by the pandemic, Hospis Malaysia began its e-learning modules for undergraduate medical students.

### • NOVEMBER

Treasure Hunt went digital

Not cancelled, but replaced. Hospis Malaysia's signature annual charity event took on a virtual form.



### • DECEMBER

Gift-shopping at the e-Bazaar

Shopping for a good cause for Hospis Malaysia continued with the charity bazaar going online.



## 2021

Throughout the pandemic and the various movement control orders, our clinical team continued with home visits and patient care, keeping patients safe at home.



- FEBRUARY - MARCH  
“I have been vaccinated!”

Clinical team vaccinated to enable them as frontliners to continue their work with their patients.



- JULY

Yayasan Sime Darby (YSD) increased support

As an affirmation of their continuous support for Hospis Malaysia's work, YSD extends their funding assistance to 7 palliative care nurses.



- OCTOBER

Around the world virtually from wherever you are!

The annual Treasure Hunt followed last year's footsteps and went online in 2021 as well, with a bumper number of participants.



### “Palliative Care in Public Health Crisis”

Hospis Malaysia organised this webinar by Professor Wee Bee Leng, National Clinical Director for End-of-Life Care, NHS England.





# Pushing boundaries for patient-centred community palliative care

At the heart of palliative care is the patient. And with access to it, patients and their families can experience the quality of life they deserve. That is why despite the many challenges the development of palliative care faces across the world, including Malaysia, from misconceptions and lack of awareness to funding gaps, and in the last 2 years the Covid-19 pandemic, Hospis Malaysia remains steadfast in reaching out to patients and their families to support them so that they can continue to live life with comfort and dignity.

It is with this, Hospis Malaysia hopes that the many lives it touches, helps make a difference, and this will be a testament to the benefits of good palliative care.



## “The nurse brings peace to my heart and home.”

– Mohd Shukor bin Kisan,  
76 years old,  
prostate cancer patient.

A van driver who knew how important his service was to the families who relied on him to ferry their children to-and-from school, En. Shukor worked through even with the pain in his hip. Until one day he was unable to get up and the pain became excruciating.

That was the start of a life he never imagined he'd have. While prepping for a hip operation, a scan showed that he has prostate cancer. “I couldn't accept it,” En. Shukor recalled. He also had to deal with the unbearable pain amidst his family's and relatives' concern over his use of pain medication.

However, he gradually came to terms with his condition and was in a better state of mind when he was assured that support is available to help patients live life even with a serious disease. And in May 2020 soon after the Covid-19 pandemic reached the shores of Malaysia, several months after his diagnosis, he was referred to Hospis Malaysia. Despite strict movement controls, with a palliative care nurse visiting regularly to help him manage his pain and other symptoms, he became more assured of the support and began to feel a sense of relief.

“I told the nurse that I won't live long. And she told me about patients who were far worse than me who are still here and keeping well,” En. Shukor chuckled. While he was told that palliative care support can help him regain his quality of life, it was from experiencing the journey himself that he really felt the difference it can make to his life. As his cancer had spread to his bones, he was thankful the palliative care team continued to monitor his well-being at home, reducing his hospital visits throughout the pandemic. “They were mindful of my

fragility and risks of falls and helped my family ensure the house environment was friendly for me, while teaching me to remain mobile,” he added.

En Shukor had one last parting comment – “Not only did they look after my physical well-being. They were also inquiring on my mental state. They asked if I had any wishes I wanted to fulfil. I merely mentioned that I would love to get in touch with a foreign friend I met more than 30 years ago when he visited Kuala Lumpur. The search took some time but they (the palliative care team) took the trouble. They eventually found him and we reconnected through a videocall. An unbelievable moment that I didn't think was going to be possible!”

For En. Shukor, it is more than just the support and care from the palliative care nurse. It is also the company of someone akin to a caring friend who is all ears to his thoughts. In his words – “The nurse brings peace to my heart and home. She makes me look forward to living every day.”



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they look after my  
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## “What I couldn’t make my family understand, the palliative care nurse could.”

- Michael Tan, 62 years old,  
Recurrent Coronary Artery Disease.

After a stroke in 2009, Michael has had ongoing issues with his heart. In 2021, after his discharge home following a coronary artery bypass graft surgery, he continued to experience chest pains at the wound site, shortness of breath and a lack of appetite. Most of all, he was feeling tired all the time. A great deal of physical troubles for a man of his age to be subjected to.

An initial request for the loan of a hospital bed led to a discussion on his underlying condition, and how else Hospis Malaysia could support him, given his discomfort and lack of quality of life. With a referral to Hospis Malaysia, a palliative care nurse started visiting him. Initial conversations revolved around the role of Hospis Malaysia and palliative care, as Michael and his wife, the main caregiver, had no idea what the organisation and the support it can provide them was all about. These talks prompted them to begin asking questions, with medications being one of them.

“I told the nurse that I think I’m taking too much. And that even with all the medicine, I’m still in pain,” Michael recalled. By sharing what he thought could be the problem, the palliative care team deduced that one of the main issues was to manage his pain first. This took a while as the nurse monitored the progress of his pain management and adjusted the medications accordingly.

“Now, the pain is better controlled. But I’m still getting weaker. And it’s tough to explain this to my family. When I tell them I’m tired, they will ask me what I mean by “tired”. When I say my heart feels tired, my wife would tell me my pulse is ok,” Michael lamented. It was after the palliative care team explained to the family that the



condition of his heart was deteriorating that they finally understood better why he was feeling that way and what it might mean. “What I couldn’t make my family understand, the nurse could,” he said with a smile.

It was more than just the palliative care team’s ability to facilitate such conversations that gave Michael peace of mind. “Hospis Malaysia looks at everything around me, including what I need, to ensure I’m as comfortable as possible. When they found out that I sometimes suffered episodes of breathlessness and needed oxygen support, they suggested an oxygen tank be made available on standby. And my son collected it on the same day from their centre,” Michael shared.

The support he receives has also helped him move on from dealing with his physical discomfort to putting some personal affairs in order. He has since completed a recording of himself sharing his life story for his grandson who is now still a baby.

“With the advice of the nurse, my family has given me a number of milestones to achieve,” Michael chuckled as he looked at his grandson in adoration. He clearly wants to live up to some of those wishes, even though he’s prepared to leave when the time comes. And for now, he aims to fulfil his daughter’s wish for him to see her walk down the aisle.



**“With Hospis Malaysia supporting us, we have a direction on how to manage our daughter’s condition.”**

– Nadia, mum and main caregiver to 7-year-old Orqed who has Batten disease.

From the many family photos adorning the walls of their home, it’s hard not to regard this young family of four as a happy one. But their blissful life isn’t without its share of trials and tribulations. After the first few years of normal happy growth, their daughter Orqed who used to like singing and dancing was diagnosed at 5 years old with a life-limiting genetic disorder that results in seizures, vision loss and cognitive failures.

“We were in denial,” Nadia said. They started researching and thought that she might get better with therapy, as her condition didn’t seem very debilitating then.

“We were still hoping,” Faris, Orqed’s dad disclosed. But as time went by, they could see Orqed regressing. After they got to know another family whose 2 children also had the same condition and realising that there is no cure, Faris and Nadia started to accept the situation. It was acceptance that they drew their strength from, to move forward and focus on spending as much time as possible with her.

In March 2022, after Orqed was admitted to the hospital and the doctor saw that her condition had progressed, he suggested a referral to Hospis Malaysia for palliative care support at home.

The support from Hospis Malaysia has alleviated the parents a great deal, amidst their struggles of looking after Orqed 24-7. One of the differences made in their lives is the reduced need to bring Orqed to the hospital every time a health issue crops up. “Before this, we had no idea what to do when she suddenly got unwell. We kept asking questions that we didn’t have answers to.

Because very little is known about the disease, we never know when it’s an emergency, when it’s not. And a trip to the hospital is very stressful for us. So now we can call up the nurse. She’ll come over to check and advise us if we need to go to the hospital or not. With Hospis Malaysia supporting us, we have a direction on how to manage her condition,” Nadia shared.

She went on to relay an incident where she gave Orqed medication that she didn’t know her husband had given earlier. “I panicked and rang Hospis Malaysia. The on-call nurse checked with their pharmacist and I was immediately assured that the extra dosage was still safe for her. We were just advised to monitor her for additional drowsiness which may suppress her breathing. And she was fine. Imagine how relieved I felt.”

The medical support Hospis Malaysia is providing Orqed helps assure her parents that she can mostly be supported at home and allay their fears in times of doubt and uncertainty. “We’re not left on our own feeling helpless,” Faris admitted. And this helps them live up to their newfound purpose, now that they’ve come to terms with the reality of it and know that there is a team supporting them with what lies ahead. By being at home, they get to spend time as a family, and this is equally important as Orqed has a 10-year-old brother, Thaqif.

“We just want her to be comfortable and without pain, while we want to continue making memories with her as a family while we can,” Nadia said with a smile.





## “She wanted the good work to continue.”

- Chew Beng Lin, daughter and caregiver to Datin Tan Chooi Hong who was diagnosed with pancreatic cancer.

“She was a very bubbly person by nature. You’d never think she was ill. But you know how a life-limiting illness can break even the strongest and most jovial.” That was Beng Lin’s description of her late mum, Datin Tan, whose diagnosis came at a time when she should be enjoying her golden years after choosing to leave a career in nursing to devote her life to the family.

When they first found out of the news, it was an emotional roller-coaster ride for everyone. Then Datin Tan did some soul searching and her spirit picked up gradually. But the challenge was just about to begin. So with some knowledge Beng Lin found about palliative care from a book she read, she initiated the idea of engaging Hospis Malaysia’s support.

The family was open to it and that decision was all it took to enable the family to focus on spending time together. Even though they weren’t afraid to talk about death, there were still issues and questions that skipped them. “The nurse brought out many questions that we, including mum herself, would never have thought of - how she wanted things to be, how she wanted to be cared for and where she wanted to be towards the end etc,” Beng Lin said.

What also comforted Datin Tan was knowing that the palliative care team was there to support not just her but also Beng Lin and her father who were caring for her. It also gave her son who lives abroad and was unable to travel back during the pandemic, peace of mind that his mum was in good hands. The team would often check on how both father and daughter were coping and assured them that it was necessary to take a break from their caregiving duties every now and then.

“They took away a lot of our stress as inexperienced caregivers. If mum was unwell suddenly, I could call from home and get advice immediately,” Beng Lin recalled. That’s why she believes that early referral to palliative care is important. “It helps give the patient quality of life right from the start. You don’t have to suffer on your own all the way. You don’t seek help only near the end. It doesn’t work that way.”

Beng Lin’s father has been supporting Hospis Malaysia for a long time without knowing that they’d be in need of its service one day. And in early 2021, when the family visited Hospis Malaysia, Datin Tan personally made a donation, emphasising that she wanted more people to benefit from its work the way she and her family did. “She wanted the good work to continue,” Beng Lin added.

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## “Helping patients accomplish their care goals is a privilege.”

- Tan Sian Chze,  
palliative care nurse.

“When people ask me what I do, I tell them that I don’t work in a hospital. The patients under our care are usually very sick and prefer to be at home. We help improve their quality of life and ensure that the caregiver or family member(s) knows how to care for the patient at home,” says Sian Chze who joined Hospis Malaysia to train as a community palliative care nurse in 2019.

“When a patient and the family are faced with the diagnosis of a serious illness, they often do not know how to handle the situation. The journey can be very stressful.” One of her biggest challenges is dealing with a multitude of viewpoints and suggestions from family and friends on what is best for the patient. These well-meaning suggestions can lead to more suffering for the patient and the family, especially when anecdotal ideas based on social pressures and cultural taboos are introduced. In situations like these, Sian Chze tells us she will keep engaging with the patient and family to address their concerns, manage their expectations and offer them relevant information to help the patient decide on his / her goals of care to achieve a good quality of life.

Good palliative care requires a good understanding of the patient as a person and of what is important to him / her in all aspects. “This is where good observation and communication skills are essential to enable us to build rapport, ask the right questions, process the response and know how to approach the issues,” she continues.

Sian Chze cites the case of an elderly lady who was under her care for 3 years. She had cancer and age-related frailties with elderly siblings as caregivers. “Through the first year, the patient was miserable,

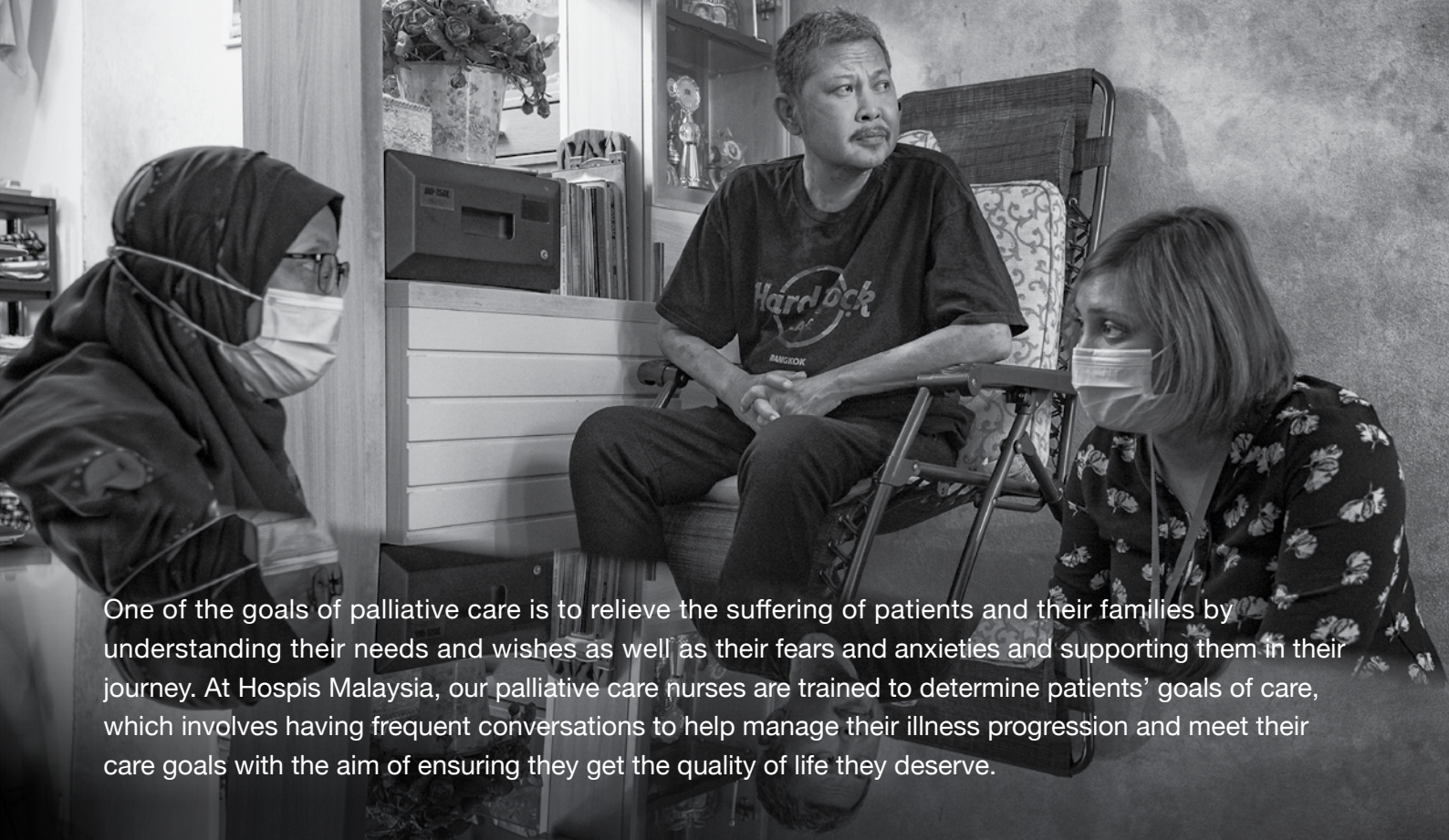
reserved and not welcoming. She had endured significant discomfort – pain, various chronic infections and constipation. Yet she wasn’t keen on taking the medication we prescribed, believing that side effects of western medicine were harmful. Then I learned from her sister that personal hygiene was very important to her when she was independent. When I noticed that her toe nails had grown very long, I deduced that it must have been difficult for either the patient or her siblings to cut them. So I offered to do it for her. To my surprise, she allowed me! Soon after, she opened up and started trying the medication I suggested, including pain medication.”

Having experienced good nursing care with significant relief from pain and infections, meaningful goals of care discussions were possible. Over time, the elderly lady took control of her life by letting Sian Chze know what she as her palliative care nurse could do to further improve her comfort and quality of life, which was clearly important to her. “She always welcomed me with a smile. This reminded me how privileged I was to have journeyed with her,” Sian Chze shares. “My sense of achievement comes from knowing that my patients have benefited from our care, that they’re comfortable and have more good days in their journey with a serious illness, and that the family is coping with less stress,” she explains. That’s what inspires Sian Chze to keep doing what she does.

As a trained palliative care practitioner, Sian Chze explains that she will work with the patient to determine his / her goals of care. This will involve conversations (often many) to help them determine what is important to them at this stage of their lives and what they’d like to achieve in the limited time they’ve left. “So as we’re discussing this, we’ll help them determine how they’d like to be cared for, where they’d like to spend the final stage of their lives and who they’d like to make decisions for them when they can no longer make them for themselves. These are their goals of care. Once this is done, our job is to then help them achieve these goals. We should also from time to time recheck with them if the goals they determined earlier still hold. This is a dynamic process that requires us to continuously work with the patient to ensure they’re as comfortable as possible throughout their journey.

This is why I feel so privileged doing what I do.”



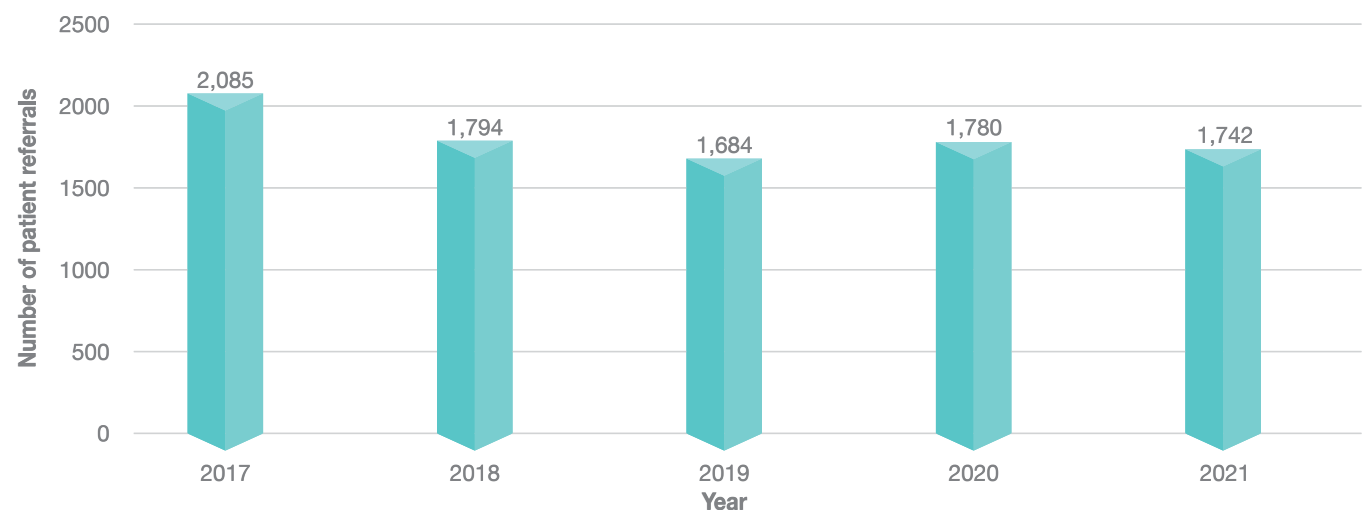


One of the goals of palliative care is to relieve the suffering of patients and their families by understanding their needs and wishes as well as their fears and anxieties and supporting them in their journey. At Hospis Malaysia, our palliative care nurses are trained to determine patients' goals of care, which involves having frequent conversations to help manage their illness progression and meet their care goals with the aim of ensuring they get the quality of life they deserve.

## Report Card

During the period 2017 to 2021, patient referrals have averaged about 1,800 patients per year. Our nurse-to-patient ratio was maintained at around 1:40. Since 2016, we have stepped up our frequency of contact with patients as part of our effort to improve our quality of care. The contact with patients is a combination of home visits and phone calls, and this has averaged 11,750 home visits and 27,820 phone calls each year during this period.

### Number of patient referrals - 2017 to 2021



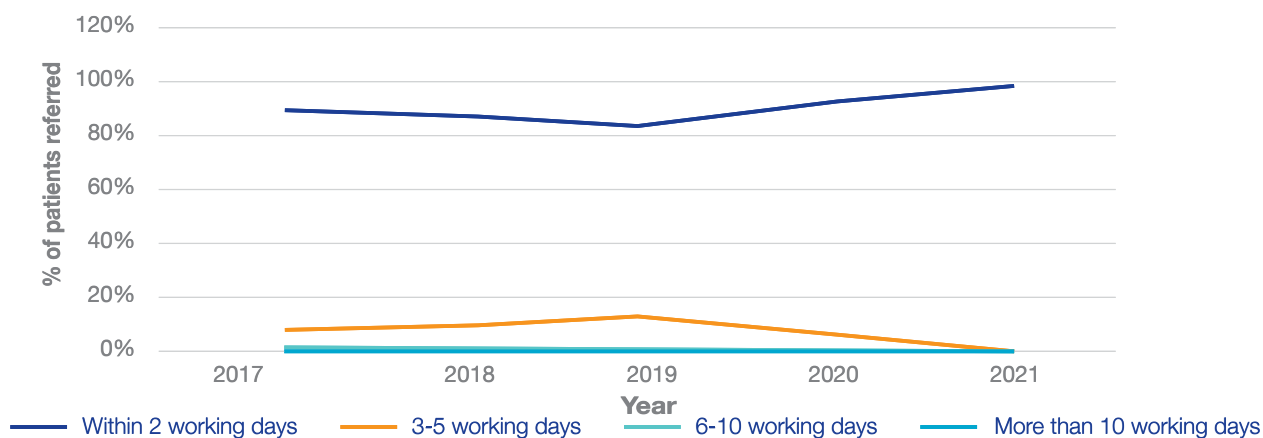
Year	2017	2018	2019	2020	2021
No. of referrals accepted	2,085	1,794	1,684	1,780	1,742
No. of home visits	11,720	11,686	12,795	11,231	1,272
No. of telephone calls	25,905	24,869	26,209	29,854	32,263
No. of emergency visits	232	149	152	120	105
No. of emergency calls	1,623	1,482	1,546	1,642	1,591



## Some Quality Of Care Indicators

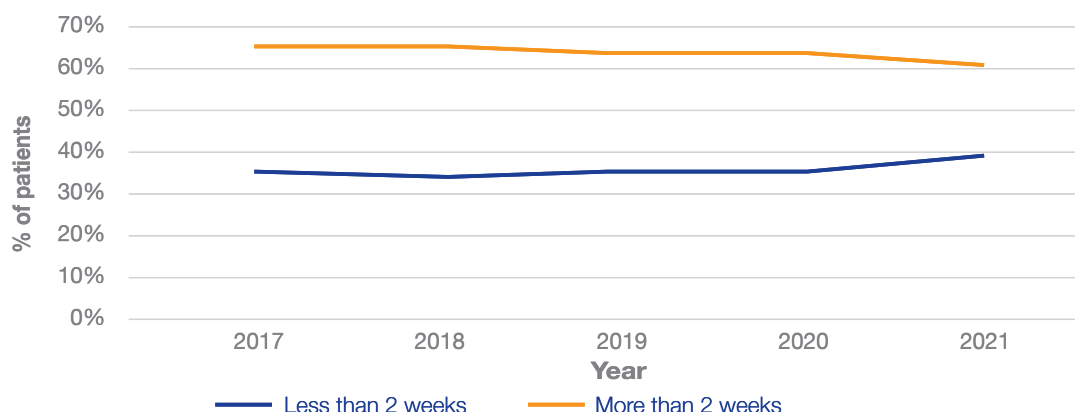
### Time taken to respond to referrals

One of the process indicators we monitor to help inform on our quality of care is the time taken to respond to a referral. During this period, we have improved on the number of referrals we have been able to respond to within 2 working days (in 2021: almost 99% of referrals), with the balance attended to within 5 working days. This is important to ensure that our care is delivered to the patient as soon as practicable.



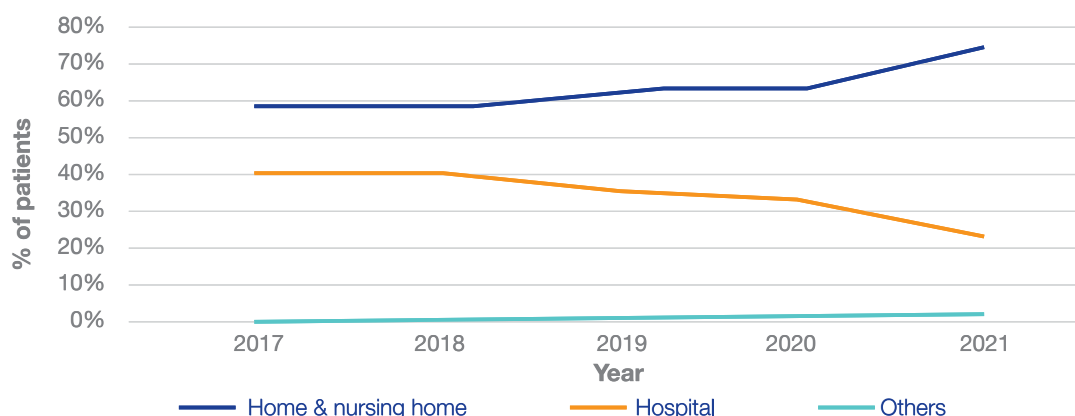
### Patients' length of care - 2017 to 2021

Increasingly Hospis Malaysia is seeing patients referred to us in the community at a very late stage of their illness, resulting in many more patients coming under our care for less than 2 weeks. With this relatively short period, often this means that less can be done to help them improve their quality of life, and much of the care then is supporting the patient and family for their end-of-life needs.



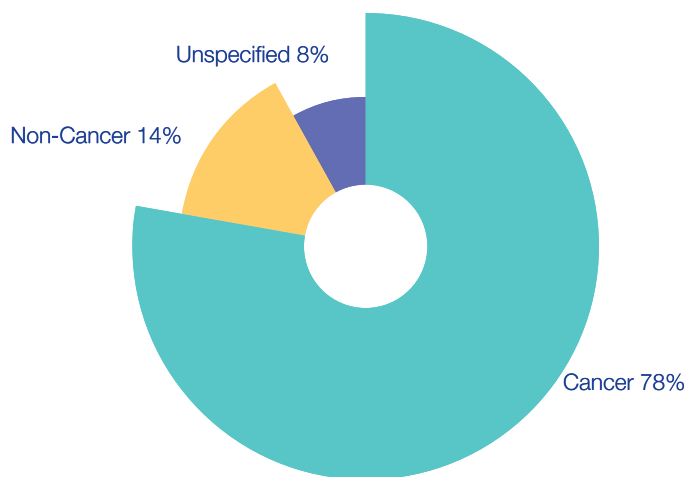
### Patients' place of death - 2017 to 2021

During this period, there had been a significant increase in the number of patients under our care who have passed away at home or nursing home as compared to in the hospital. While we have no further statistics on whether home / nursing home is their preferred place of death, it is a significant enough trend to inform us that patients whom we care for in the community have not had the increasing need to be rushed back into hospital towards their end of life.

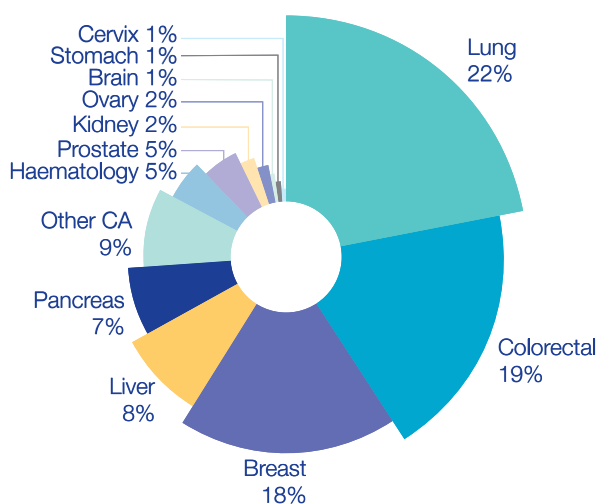


# Our Patients: Types Of Illnesses

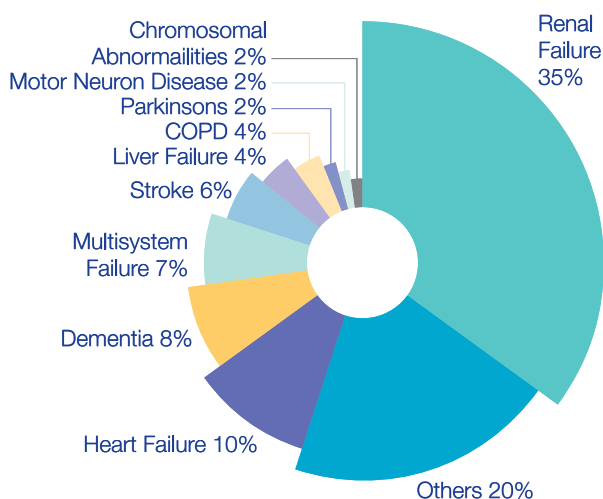
Type of life-limiting illness of patients referred from 2017 to 2021 (Total: 9,085)



Type of cancer for patients admitted from 2017 to 2021 (Total: 7,129)




Type of non-cancer patients admitted from 2017 to 2021 (Total: 1,290)









## Teaching, training and collaborating

The Ministry of Health estimates that every year almost 200,000 people in the country face serious health-related suffering and will require palliative care. And with less than 10% currently able to access it, there is still much to be done. In a country with a population of 32 million covering almost 330,000 km<sup>2</sup>, we recognise that we cannot reach every patient and family in need. It is therefore important that this pillar of our work continues to develop to ensure that we learn and train from the best, and teach and train others to do the same.

## Teaching And Training

Globally, it has been determined that almost 57 million people require palliative care each year. And currently only about 14% have access to it. In Malaysia the inequity to access is similar – almost 90% of people in our country currently still do not have access to good palliative care, and this is a poignant reminder that more can be done to improve this access. It has also been identified that the 3 main barriers to the development of palliative care are:

1. Policy
2. Education
3. Availability of Medicines

While Hospis Malaysia continues to engage with policy makers to implement policies for the inclusion of palliative care in our country's universal healthcare provision, and to ensure adequate availability of essential medicines for the control of pain, it has over the years focused definitively on building a good foundation for palliative care education and training to healthcare workers and medical students.

The vast majority of health professionals worldwide have little or no knowledge of the principles and practices of palliative care although a growing body of knowledge has been accumulated over the past 50 years on the science of palliative care and palliative medicine.

In response to this, Hospis Malaysia's has a multi-pronged approach to its work in education and training:

### • Undergraduate and post-graduate medical student teaching and training

This consist of a blended approach of lectures and tutorials, enhanced with attachment programmes with our clinical team to introduce concepts of palliative care to medical students. This is offered to most of the major medical schools in the Klang Valley, and over time as our e-learning platform develops, online learning modules can be made available to other medical schools across the country. During this 5-year period, 3100 students were taught and trained at Hospis Malaysia.

### • Asia Pacific Hospice Network (APHN) collaborative workshops

Each year we organise a series of workshops focusing on different aspects of palliative care for healthcare workers to enable them to identify their patients' palliative care needs, and potentially to address some of the patient's basic issues.

These workshops range from palliative care nursing training, dealing with hope and suffering to drilling down to more specifics on pain and other symptom management. During this 5-year period, over 1000 healthcare workers attended the workshops. Workshops were suspended throughout the pandemic from March 2020 until mid-2022.

### • Training of palliative care trainee specialists

This programme is part of the Ministry of Health's training of their palliative care specialists, which provides trainees with 6 months of exposure to palliative care in the community. The training is a 6-month attachment with regular one-to-one teaching with our senior doctors coupled with on-the-job training with the clinical team. During this period, 18 trainee specialists were trained at Hospis Malaysia.

### • Offsite workshops and training

Our senior clinicians continue to be invited to facilitate workshops on the practice of various aspects of palliative care. During this period, some of their notable involvements in such workshops include:

#### 1. RESPIRE

Our clinicians have been involved in a research project to identify severe suffering and unmet needs in patients with advanced chronic obstructive pulmonary disease (COPD), and this led to a role to build capacity for supportive care for these patients. This is part of a larger research initiative on improving respiratory health across Asia by the NIHR Global Health Research Unit on Respiratory Health (RESPIRE), an international collaboration spanning Bangladesh, India, Malaysia and Pakistan, working collaboratively with The University of Edinburgh to improve respiratory health across Asia.



The training done by our clinicians in this project include:

- Introducing the concept of palliative care for severe COPD patients and how it can support them and their caregivers to cope with the illness
- Supporting the building of local education capacity and to develop a faculty with the knowledge and training skills to deliver effective workshops for palliative care for severe COPD that are relevant to the local situation and can be embedded in local clinical practice and pathways

## 2. One of our doctors presented at Hospital Selayang: “What Happens to Patients Referred to Community Palliative Care?”

To provide doctors at MOH hospitals who are counselling patients and discharging them back into the community a better understanding of Hospis Malaysia’s role in Community Palliative Care, so that they are able to reassure their patients how they will continue to be supported and to make the patient’s discharge home as seamless as possible.



## 3. Hospis Malaysia organised a symposium on “Standards & Quality of Care Indicators in Palliative Care”

The symposium provided a platform to discuss the importance and relevance of standards and care indicators. Speakers from low-resourced countries shared their experiences of how setting some preliminary palliative care standards is useful and can be done. The symposium focused on the importance of getting the framework for standards started, so that patients and families are provided with a benchmark of what to expect from a service. It also enabled a healthy exchange of knowledge and experience between leading international practitioners and Malaysia’s cohort of palliative care practitioners.



## 4. REBUNG (REDUCING BARRIERS IN CANCER - EARLY DIAGNOSIS IN THE URBAN B40 (uB40) Group

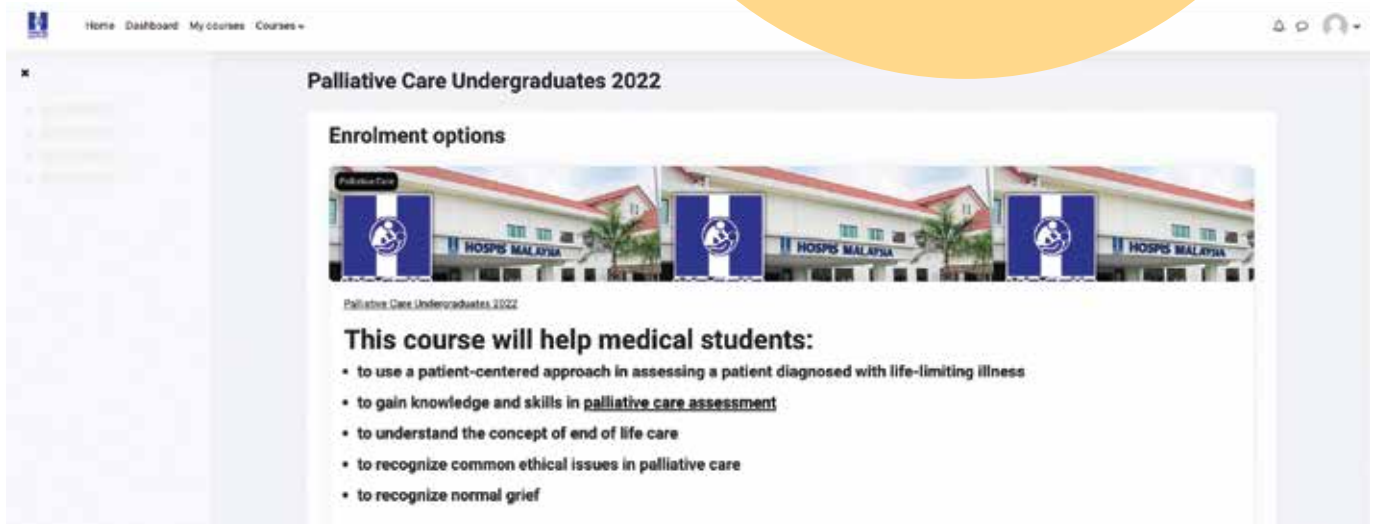
Hospis Malaysia lends support to this University Malaya-led cancer care initiative by providing more information about our palliative care service. Recognising the substantial gap between the higher prevalence of chronic diseases among the urban poor and the low percentage who seek treatment, the project aims to “bridge the cancer gap”. REBUNG’s aim is to link existing cancer organisations that are already providing support in the community to enable better care coordination and access to care.





## e-Learning

The Covid-19 pandemic which began in March 2020 has been a mixed blessing for Hospis Malaysia. While it led to significant disruptions to our service initially due to challenges of infectivity and ongoing travel restrictions, it also accelerated our need to explore new ways to deliver our teaching and training activities.



With the cancellation of face-to-face teaching at the onset of the pandemic, Hospis Malaysia maintained its view on the importance of teaching and knowledge sharing. Our philosophy of teaching the knowledge which is to understand the evidence behind palliative care practices could continue, although the training of skills required to put the knowledge into practise was likely to be difficult until physical attachment for students could resume. By September 2020 an e-learning platform was developed, and this enabled students to pursue the learning in their own time and access it from wherever they were at. This helped make some parts of palliative care education more accessible to more students.

Available to both undergraduate and post-graduate medical students, the online programmes are typically a blended learning made up of recommended reading materials, videos and interactive quizzes where students respond to problems presented and trainers assess them equally as conveniently.

The development of this e-learning platform is now an evolving process. Even as in-person sessions are gradually resuming, the digital learning programmes available are continuously being reviewed for content and user-friendliness. Plans are in the pipeline to open our e-learning platform to medical schools across the country that have little or no palliative care teaching, for use as a standalone module. One of our targets is to roll out a post-graduate version in the next year that can be offered to Family Medicine Specialist trainees.

## Some Statistics On Our Teaching And Training

### Number of participants (2017 - 2021)

TYPE	NO. OF PARTICIPANTS
APHN collaborative workshops	1,025
Medical undergraduate lectures & tutorials	2,987
Postgraduate Family Medicine lectures & tutorials	113
Postgraduate Family Medicine attachments	113
Palliative Care Specialist Trainees	18
Others	318

### Where we taught and trained (2017 - 2021)

	Undergraduate Medical Students	Family Medicine Specialist Trainees	Palliative Care Specialist Trainees	Others (Nurses & other allied healthcare)
Universiti Malaya	872	65	-	-
Universiti Putra Malaysia	467	13	-	-
Universiti Technology Mara	908	35	-	-
Universiti Pertahanan Malaysia	544	-	-	-
Perdana University	196	-	-	-
Ministry of Health	-	-	18	-
Others	1	-	-	317



*Palliative care specialist trainees*



*Nurses and other allied healthcare*



*Undergraduate medical students*

## The Palliative Care Specialists Who Have Trained With Us

Since 2013, Hospis Malaysia has been working with the Ministry of Health to train their palliative care specialist trainees. In the 9 years since the establishment of this specialist training programme, 30 specialist trainees have elected to attain their 6-month community palliative care training at Hospis Malaysia.

As a leading teaching and training centre, the 6-month curriculum for the specialist trainees at Hospis Malaysia aims to equip them with the knowledge and skillsets to assess, diagnose and treat distressing physical symptoms associated with a life-limiting illness and empowering them with the ability to look beyond the diagnosis of a disease and understand the impact of the illness and how that affects the patient physically, psychologically, spiritually and socially.

In the course of this, they are also trained to communicate and discuss difficult issues with patients and families, to enable them to understand what may lie ahead and what to expect as they journey through the illness. And finally, they are trained to support patients at their end-of-life, to ensure a peaceful and dignified death. The time spent in the community also enables the trainees to understand and address issues patients and families face when they are discharged, as often these issues do not surface when they are treating them in a hospital setting.

Dr Anila Perumal who is currently the palliative care consultant at Tuanku Ja'afar Hospital, Seremban and Dr Saiful Adni Abdul Latif the palliative care consultant at Malacca General Hospital, each spent 6 months training at Hospis Malaysia. Here they share their experiences and how time spent at Hospis Malaysia has equipped them to develop into leaders in the respective communities they have been assigned to.

### “Working in palliative care allows me to become a better doctor.”

- Dr. Saiful Adni Abdul Latif, Palliative Care Consultant at Malacca General Hospital.

For someone who was also interested in the psycho-social impact his patients may be experiencing, palliative care was like a calling awaiting his discovery.

It was during his time as a houseman that Dr. Saiful found out about palliative care. “It opened my eyes to how it can help with the management of patients with life-limiting illnesses,” he shared. Eventually his deepening interest led to his decision to specialise in palliative care.

“Some of us think that problems will sort themselves out once we discharge patients. But most of the difficulty come after they're discharged. So it's important to spend time in the community as we're able to help them better in their own environment and offer care that meets their needs,” he explained.

At Hospis Malaysia, he learned how to support patients with evidence-based ways of managing different illnesses and symptoms. “I'm not just addressing the diagnosis. I'm actually helping the patients themselves as a person going through a difficult situation, whether physically, psychologically, socially or spiritually.”

The community experience he gained goes beyond patient management. Tasked to lead the development of palliative care in Melaka, his job often involves sharing knowledge with others and his experience has helped him provide guidance to everyone working in palliative

care in the community. His attachment with Hospis Malaysia also added to his management and leadership skills, problem-solving abilities and knowledge in organising courses and advocacy programmes. All these are valuable to his efforts that are aligned with the national development plans for palliative care, as Dr Saiful and team are working on improving the provision of palliative care in the state on every level, from staffing to training to requisitioning for resources.

“When I was asked in my 1st interview on why I want to be a doctor, I remember saying I wanted to help people. Well, now I can actually say that I am helping people.”





## “Palliative care is the best kind of medicine for my practice,”

- Dr. Anila Perumal, Palliative Care Consultant at Tuanku Ja'afar Hospital, Seremban

In her path towards becoming a medical officer, Dr. Anila had spent time in different hospitals and departments as part of her learning experience in the real environment. It was here that she came across many patients whose illness could not be reversed or cured. “I felt something was missing in what I had learnt to date, and my practice,” she shared. That inspired her to seek the knowledge to better equip herself.

“Palliative care is very holistic. It includes everyone around the patient and every aspect of his / her life too.” She found that her years in palliative care are one of the best as it's the type of medical practice she'd always wanted to do but never had the exposure and knowledge.

From her 6-month stint with Hospis Malaysia, she saw the importance of community training. She discovered that the ward and the home present 2 different pictures. “We may send them home with a good discharge plan but once you go into the community, you can see if it translates well into the home environment or not. And most of these patients want to be at home,” she explained. Understanding the setting where the patient is going to be most of the time can help them tailor plans that fit the patient's needs.

This proved to be very helpful for Dr. Anila as she was just starting on her role as a palliative care specialist when the Covid-19 pandemic struck and nobody wanted to be in the hospital. “Community service became very crucial. I was glad I had the training as I knew how to support my patients at home during that crucial period,” she said.


Apart from developing palliative care at the hospital, Dr. Anila is also working on growing the service at the community level in the state with the organisational and managing skills she gained from Hospis Malaysia. The training and teaching skills she garnered during her time at Hospis Malaysia is also helping her, now that she's required to teach and train others who are working in the community in her location of coverage.

“We need to understand what our colleagues working in the community are encountering and support them to improve the delivery of their service. For instance, often patients and their caregivers at home don't know how to administer or are afraid to use the drugs prescribed. It's therefore important for us to fully understand the issues and work out a way to train our colleagues to work with the patient or the caregiver, so that the medication is taken or administered according to the prescribed dosage and frequency. This may seem trivial, but it's all important if we are to manage the patient's symptoms properly at home,” she commented.

Dr. Anila believes that if one were to take up palliative care training, the key is to re-learn medicine from a fresh perspective. “Be open to the idea of letting go of all the things you've picked up. And then re-frame your ideals, your mindset and your goals.”







# Advocating for patients and their families

Hospis Malaysia's drive to create greater awareness about the benefits of professional palliative care in its effort to promote better access, require the committed effort of many. It takes a multitude of individuals internally and externally, as well as networks of collaborations to give the organisation the ability to navigate the infinite journey ahead in advocating for the rights of patients and that of their families.

The journey involves continuous stakeholder engagement with a mission to influence policy changes, healthcare professional cooperation and public perceptions. We are always appreciative of the support from everyone who has joined us on this road to achieving the vision of making quality palliative care accessible to all in need.



## Public Advocacy

After spending 20 years building patient services and an education platform to train the next generation of practitioners, Hospis Malaysia began focusing on public advocacy to improve public perception and increase awareness about palliative care. Recognising the good following and community engagement at its various fund-raising events, Hospis Malaysia went on to build on the encouraging response to drive greater awareness among the public, paving the way to public advocacy taking its place as one of Hospis Malaysia's key pillars.

At the start of 2016, Palliative Care Awareness Month (PCAM) became an annual feature. As the event gained traction, more activities were included, from patient and caregiver testimonials to a digital dimension that proved to be invaluable during the pandemic in 2020.

Concurrently, online videos were also curated to provide a more dynamic understanding of our work.



### Annual Palliative Care Awareness Month (PCAM)

With the yearly theme adopted from the World Hospice and Palliative Care Day (WHPCAD), PCAM in April is an annual advocacy initiative by Hospis Malaysia to educate the public on the importance of improving access to professional palliative care.

Month-long activities and public events organised by Hospis Malaysia or by “ambassadors” and partner organisations were held to highlight the plight of people whose lives have been affected by a serious illness. Educational contents in the form of posters and videos on living life with dignity despite a life-limiting illness were developed.



*Promoting palliative care through all channels.*



## Filmography

A series of videos showcasing the various aspects of palliative care has been created to increase awareness and improve the public's knowledge and perception in dealing with life-limiting illnesses.



Scan for videos

### 1. Yusuf (2016)

Diagnosed with an incurable life-limiting illness, Yusuf chooses to spend his remaining days at home, surrounded by his loved ones instead of at the hospital. With the support of community palliative care, Yusuf's life at home is maintained and his quality of life improved. The benefits of community palliative care are seen to leave a positive effect on Yusuf's immediate family members. The film asks an important question about one's care preferences when faced with a serious illness.



### 2. I Wish I Had Cancer (2017)

Premiered at the Voices for Hospices Gala Dinner 2017 in conjunction with World Hospices and Palliative Care Day

with the theme "Let Us Not Leave Anyone Suffering Behind", it focuses on how palliative care helps improve quality of life by alleviating distress and suffering, differentiating between those who have access and those who may not. In this film, two friends discuss their illness and how each one's quality of life is affected by their illness. While the patient with cancer initially appeared to be in far worse condition, with the help of a palliative care nurse who made home visits, his symptoms are better-managed and is seen to be coping better. Meanwhile, his friend with COPD is seen suffering and he laments how he is unable to access palliative care services because he does not have cancer.

### 3. My Care, My Right (2019)

It highlights the rights of patients to be aware of their diagnosis, no matter how serious it is; their right to decide how they want to lead their life as well the right to express where they want to be cared for.





## “Speak Up!

### There’s an Elephant in the Room”: A 6-month long public awareness campaign

The reluctance or inability to talk about difficult issues can bring out in people a range of emotions often associated with suffering. There is a need to facilitate conversations in such cases and often it starts by helping the patient and their loved ones open up.

“Speak Up!” is a campaign that aims to empower patients and their loved ones to talk about what matters and inspire everyone to advocate for better access to quality palliative care.

Taglined “Speak Up! Let’s Start Conversations That Matter”, it was launched in KLCC Esplanade on 1 October 2018 by YB Hannah Yeoh, Deputy Minister of Women, Family and Community Development. One of the highlights of the campaign was the display of 10 life-sized elephant sculptures at KLCC Esplanade for 14 days before being relocated indoors in Suria KLCC. To create the Cik Gajah series, Hospis Malaysia collaborated with the late Yusof Gajah, Malaysia’s foremost naïve art painter, and brought the sketches to life together. To raise campaign profile and extend its reach, Hospis Malaysia partnered with corporations that went on to adopt the elephants with the respective organisation names featured on the sculptures.

The 10-foot-high installations attracted the attention of thousands of visitors and sparked a movement to encourage patients and families to speak about what matters to them and their quality of life. The buzz generated also helped bring to the fore the message that facilitating conversations is the central practice of palliative care.



*Creating awareness with the support of outdoor media spaces and government officials.*



*The late Yusof Gajah personally autographing the “Speak Up” merchandise.*



*The 10 elephant sculptures at KLCC Esplanade were the talk of the town.*





*Generating buzz with patient stories and endorsement from government officials.*

*Public participation activities include donation pledges and thought-sharing.*

From inspiring people to talk about difficult issues to emphasising patients' rights to know and decide. In the following year, Hospis Malaysia embarked on a more patient-focused route, because when someone is diagnosed with a serious illness, it is important to ensure that the patient is at the centre of any care decisions. This led to the "Speak Up!" campaign for PCAM 2019 bearing the tagline "Speak Up – Because I Matter". It was launched at Suria KLCC on 11 April 2019 by the Deputy Minister of Health, YB Dr Lee Boon Chye.

For this campaign, Hospis Malaysia took on a more insightful approach by welcoming the public into the lives of patients in which palliative care helped make their voices heard and how that made a difference to their quality of life. A photography exhibition featuring patient stories was held, alongside an information booth to increase public access to information on palliative care and the work of Hospis Malaysia.

These story-tellers were an enlightening extension to the larger-than-life presence of the 10 elephants of the Cik Gajah series from the year before. Still on display under the same roof in Suria KLCC, the installations continued to be a reminder of how important it is to not ignore the challenging topics, with the stories reinforcing the message that a patient's quality of life matters most when faced with a serious illness.

Apart from promoting the event on-ground, the campaign was also shared online through Hospis Malaysia's social media assets and featured on outdoor digital screens including Suria KLCC's in-house digital screen. The launch attracted significant print and digital media coverage from 11 media titles, garnering RM1,200,000.00 in PR value, while the 14-day "Speak Up! – Let's Start Conversations That Matter" campaign and the 3-day "Speak Up – Because I Matter" exhibition achieved an engagement reach of almost 2 million visitors in Suria KLCC.



*A sight to behold to start conversations that matter.*





# Highlighting our financials 2017-2021

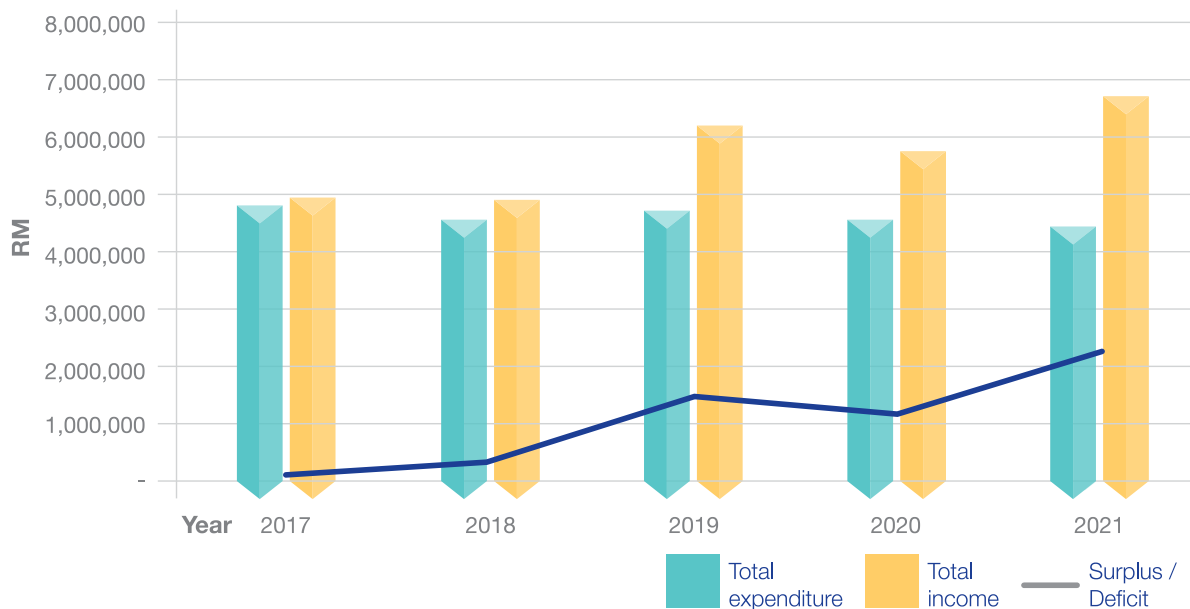
As a charitable organisation that relies substantially on the generosity of donors, partners and supporters to sustain our services, Hospis Malaysia values transparency, integrity and accountability in its financial management. Here we share with you a snapshot of the organisation's financial status to give you an insight into how we have fared over this period, and the measures we undertake to ensure the sustainability of our work.



## Managing Income To Fund Our Expenses

With a prudent financial management philosophy, there has been a conscious effort to ensure that our income generation keeps in line with our expenditure year to year. During the years of the Covid-19 pandemic, we have been fortunate to benefit from an earlier strategy of diversifying our donor base, to ensure that we are not overly reliant on any one segment of donors. The ability to move quickly to digital forms of donor engagement during the period of 2020 and 2021 also helped to sustain the steady flow of income.

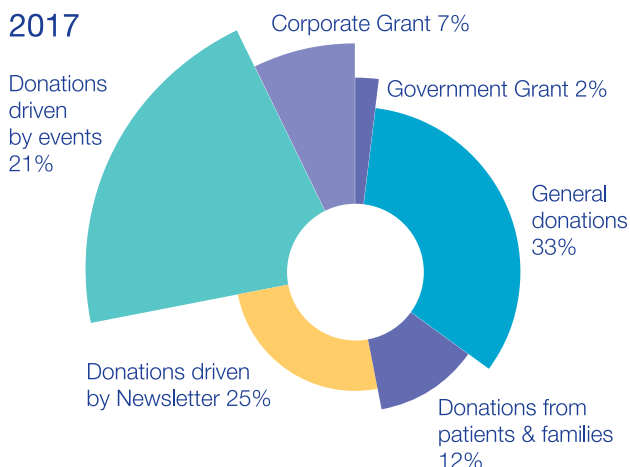
Income vs expenditure (2017-2021)



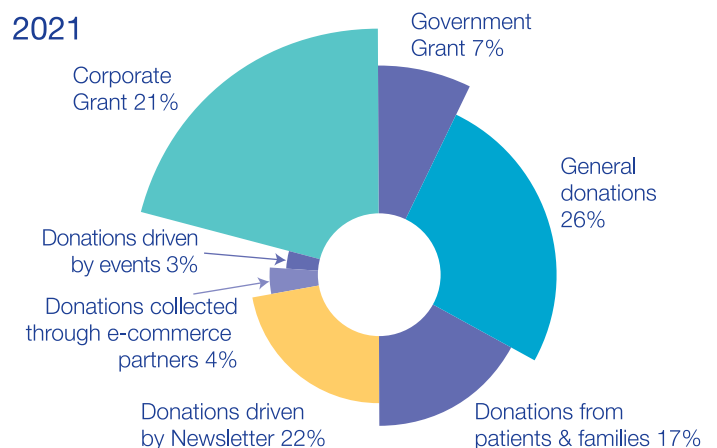
## Breakdown of donations by type: 2017 vs 2021

- During the Covid-19 pandemic period of 2020 and 2021 we experienced a significant fall in donations driven by events (21% in 2017 to 3% in 2021). This however was offset by a growing donation drive via our e-commerce collaborating partner platforms, and earlier engagements with corporate benefactors resulting in increased corporate grants.
- Corporate grants increased from 7% to 21%. Support through corporate grants tend to be committed over a medium-term period, conditional upon the fulfilment of agreed KPIs. This type of medium-term funding enables us to make more meaningful planning and projections for our work.
- Support from the government increased during this period from RM100,000 in 2017 to RM420,000 in 2019. This grant has remained stable at RM420,000 in 2020 and 2021.

### 2017

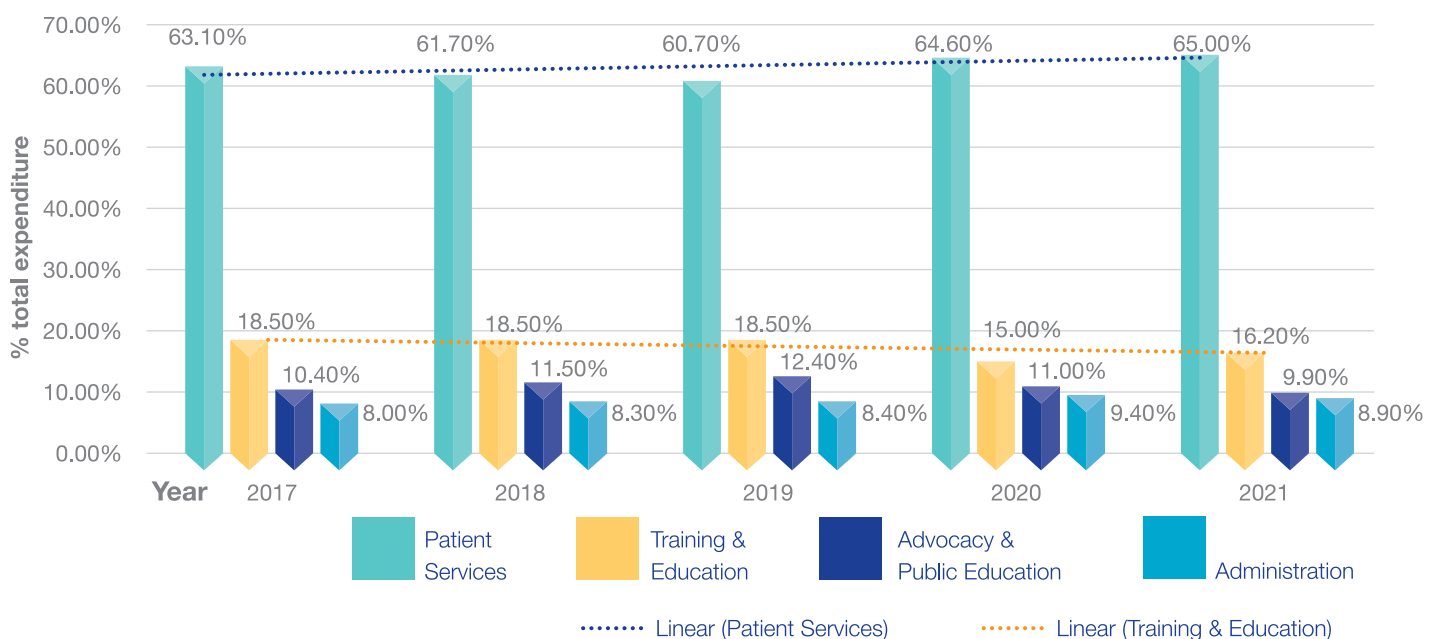


### 2021



## Breakdown of expenses (2017-2021)

- During the period of 2017-2021, approximately 80% of total spending was dedicated to patient care and education and training of healthcare professionals.
- Until 2020, there had been a steady increase in the % spent on training and education as we worked to grow our training platform to better meet the needs of the country.
- In 2020 and 2021 during the Covid-19 pandemic, much of our teaching and training activities were suspended. It was also during this period that the cost of treating each patient under our care increased. This added cost was attributed to:
  - i. Increased patient load due to more patients being referred as a result of their hesitance to return to hospital
  - ii. Additional precautionary measures taken to protect our staff as well as patients and families with personal protective equipment (PPE)
  - iii. Additional medicines and medical supplies provided to our patients due to their inability to return to hospital for follow-up prescription
- Advocacy and public education expenditure remained relatively constant between 10% - 12% of total expenditure during this period.
- Administrative costs also remained relatively stable between 8% - 9% of total cost during this period.





## Our journey in community care and patient support.

The work in palliative care and the effort to advance its access never stop. It's an initiative that we have been taking for 30 years since Hospis Malaysia began. With an annual estimation of over 200,000 people with serious illness requiring palliative care in Malaysia and only less than 10% have access to it, what we do at Hospis Malaysia has grown all the more crucial. Even when the nation was weathering through a public health crisis, our clinical team and many other community groups continued to work tirelessly to try and make a difference.

So as we reflect on our journey in the last 5 years, we would like to bring to the fore the continuous effort we take to progress palliative care in the community through various aspects, from patient services, education and training to engagement with stakeholders, government and policymakers. Let us share with you, how we have navigated the path and will continue to do so, to make palliative care more accessible to all in need, by building communities with everyone involved in palliative care and supporting the people.

Help us make a difference.