COVID-19 – IS THERE A SILVER LINING AS WE LOOK BACK AND FACE THE FUTURE?

On Jan 25th 2020, Malaysia identified its first case of Covid 19. On March 19th 2020, the first fatalities were announced. In the months that followed, the nation has been trapped in an everchanging version of Movement Control Orders(or disorders) with increasing infected cases and deaths.

The impact on individuals and their families has been severe. The nation waits on tenterhooks as the daily number of positive cases and deaths are announced daily. In recent months, pictures and stories of health devastation are portrayed in the media with sadness and blame apportioned to various parties. There is also the economic devastation to the many and the ‘white flag’ campaign demonstrating how this pandemic has made even the basic necessities of life unattainable. All this is taking place in a climate where our political leaders are jostling each other for supremacy.

Over this period, the clinical team at Hospis Malaysia and many other community groups have worked tireless to try and make a difference. Each day brings about 10 new referrals to us for community palliative care, mainly patients with advanced cancer. But in recent months, a small number of patients are now coming to us having had Covid 19. Palliative care has its role in the Covid narrative. It is about managing symptoms such as breathing difficulties, helping with communication and goals of care discussions. And in some, having conversations around grief and loss.

Until the pandemic, it has mainly been patients with life limiting illnesses that wonder 'what tomorrow brings?', whilst most in the public may take each day for granted. All this has changed with 'death anxiety' affecting many of us daily. Previously many cancer patients tended to be the ones seeking alternative and miracle remedies to cure their cancer. Today, everyone is bombarded with tales of vaccines, Ivemectin, hydroxychloroquine, steroids and other therapies that may offer a remedy for the disease. For the average person, it is challenging to know what to believe and who to trust.

With hundreds of people needing assisted breathing and intensive care treatment and many not surviving, the fear of severe illness and death pervades the community. This is perhaps when one realises what is truly important in life. Hopes and fear are intertwined and in this environment, there is the realisation that the values that underpin our humanity becomes more apparent.

Life becomes defined in the values for which we live for - such as our relationships, being respected, living with dignity and grace surrounded by what matters to us, our family and home. Family, friends and neighbours as well as the surrounding community are coming together and helping each other, sharing in the hardships and supporting each other to alleviate the burden. Perhaps the new car or the latest gadget just isn't that significant anymore.

The new normal is upon us. For industry, it's the work from home culture. In education it is about online learning but what about for all of us once this pandemic is over? Will we and should we live life a different way?

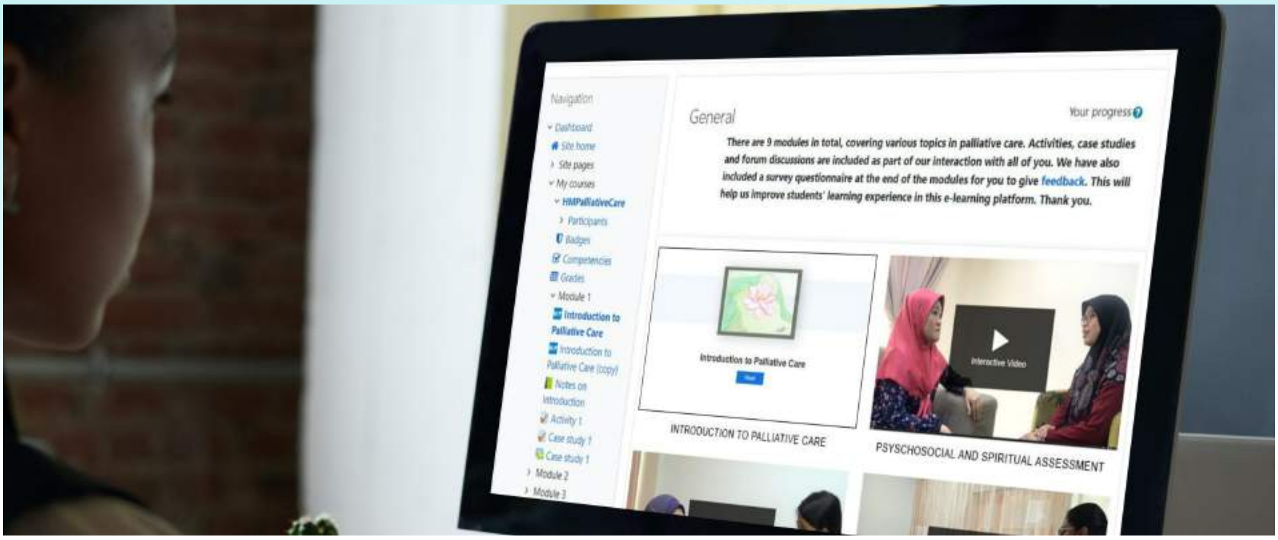
Perhaps it is about living every moment, being grateful for our ability to touch, feel and connect to the people that we value. To respect and treat others with dignity and in turn to be treated likewise. To open up to the people close to us, sharing our care preferences so that in the unfortunate event we are affected by a major illness, those that care about us will know what to do. Say the things that matter now so that we do not regret not saying so when we are unable to. Life is transient but the relationships and moments that matter will live on with others. Let the effect of the Covid 19 pandemic also be the harbinger of hope that a better humanity will surface in the country.

As with many in the community, the Hospis Malaysia family has not been spared losses resulting from Covid-19. But there is a strong resolve within our palliative care family, that our front line is the community where we live and breathe in, and our work must continue. We would like to thank everyone for their on-going support through these testing times.

TEACHING AND TRAINING
TRANSITIONING TO BLENDED LEARNING

A year ago, as the pandemic looked to be prolonged, Hospis Malaysia transitioned into an alternative teaching and training methodology to ensure that education and learning for our students continued. Digitalizing teaching and learning have become the norm across the world, and with it, challenges for both educators and learners who have had to adapt to a total virtual learning experience in a short time.

It is undeniable that teaching and training in most fields is most impactful when there is actual human interaction. In medicine, the need for human interaction is even more profound. One of most important parts of training while at Hospis Malaysia is the attachment program, when students shadow our clinical team on their home visits. The home visits provide the students with a real-life experience of what is happening to our patients at home. They see firsthand, not only the medical needs of the patient, but also the social, emotional and psychological impact of having a very ill patient at home. They witness how patients and their families cope outside the hospital environment where most doctors are trained. For Hospis Malaysia and our work in the community, it is important for all medical professionals to develop a patient-centred approach. Studies globally have shown that given the choice, most patients with progressive chronic illnesses such as cancer, organ failure and advanced neurological conditions, prefer to be cared for at home. And the pandemic has demonstrated how important it has been to be able to keep these patients safe at home.



General

There are 9 modules in total, covering various topics in palliative care. Activities, case studies and forum discussions are included as part of our interaction with all of you. We have also included a survey questionnaire at the end of the modules for you to give feedback. This will help us improve students' learning experience in this e-learning platform. Thank you.

The importance of such physical learning experiences meant that as soon as our clinical team, and the doctors under training were fully vaccinated, we resumed our home visit attachments for post graduate training with full adherence to Ministry of Health guidelines. For undergraduate medical students however, lectures and tutorials continued online, but the physical learning experience is currently still not possible. We have worked on reinventing our teaching methods so that the engagement and impact on our students remain meaningful by including a blend of recorded accounts of real patients and caregivers, and case discussions involving these encounters. This has led to some rich discussions about understanding patients' preferences, and the needs of the people around the patient.

There is ongoing evaluation of the e-learning through student feedback, monitoring student participation and their responses to questions embedded in the course. Their progress is also reviewed by their respective university lecturers. Online teaching and learning poses its own set of challenges. As our Medical Director, Dr Sylvia McCarthy shares, "Palliative care teaching content can consist of difficult ideas and concepts – which require substantial reflection and in-depth discussions, and story-telling that can invoke certain sentiments beyond theory. Teaching is much more effective when we are able to examine responses of students while being in the same room. It helps us better gauge their understanding. When the teaching is conducted online, some of this is diluted."

As we move out of the pandemic this e-learning course will form part of a blended learning approach to undergraduate community palliative care teaching. It may also prove to be a resource for those universities where undergraduates do not have access to palliative car teaching.

Despite the many challenges, Hospis Malaysia remains committed to its teaching and training activities. Exposing medical students and practitioners to elements of palliative care and introducing them to a palliative care approach to practicing medicine is key to improving healthcare professionals' ability to identify patients who may require palliative care. For how else can we improve the access of the more than 100,000 people who require palliative care each year, if the healthcare professionals to whom they entrust their care are not able to identify and address their needs.

21KM OF INSPIRATION

Jay Ren has been giving his time to volunteer at Hospis Malaysia since 2019. Witnessing how our work has impacted the lives of many with serious illnesses, Jay Ren appreciates what it takes. He then took a bold move to help us raise awareness and funds by reaching out to a wider community through a 21km Virtual Run challenge. His aim – to educate and influence his peers, family members and his extended circle of friends about palliative care.

Below is an interview with Jay Ren which we hope will encourage many more to play a role within the compassionate community that we are creating. With all on-ground initiatives put on hold due to the pandemic, Hospis Malaysia is nevertheless committed to the continuity of its service to patients and families in need. And to sustain our work, we need the community's ongoing support. We therefore call upon those who are inspired by Jay Ren's story below to join us in celebrating our 30 years of service this year through their own virtual events. Contact us at pr@hospismalaysia.org to find out how.

You raised more than RM2000 for Hospis Malaysia through "Run for Palliative Care". What inspired you to do it?

The thought of raising funds first came when a friend of mine invited me to sign up for a virtual run. I thought, "Why not, 21km?" Given that this was going to be my first ever half-marathon, I needed a boost and supporting a good cause would be a motivation. Hospis Malaysia (HM) came to mind.

My journey with HM began in 2019 when I joined as a volunteer and soon realised how little the public knew about palliative care, and the need for continuous funding from the public. So, when the opportunity came, I made a pledge to help spread awareness and raise funds for the organization.

Encouraging your circle of friends to contribute and completing the run must have been a challenge especially during the pandemic. How did you rise to it?

The greatest challenge was probably getting myself 'out there'! I was nervous especially when I had to publicize the event and call for support. Nevertheless, I was amazed by the support I received from people around me who encouraged me to complete it. It became less nerve-wrecking as the fund-raiser progressed.

I was initially hesitant in setting a high goal. So, I decided on RM1200 - approximate cost of caring for 2 patients in a month - a realistic amount I hoped to achieve within 2 weeks. When we surpassed the amount in 10 days, I raised it to RM2000. That really boosted my determination.

When it came to the run, the training was tough - being disciplined and taking the appropriate steps to recover. I learned a lot throughout the process. Running in an enhanced form and taking control of my breathing techniques. Also, how running can be an up and down struggle to greater achievements one day. On the day of the run, I put in place what I learnt and completed the 21 kilometres safely.

In Malaysia, the idea of palliative care is rather vague and is often viewed as the last stop before the end of life. Was it challenging for you to rectify the misconception among your friends and family members?

Definitely. Talking to my friends and family, I found that unless people had a personal experience (e.g. knowing someone who has received palliative care), it is common to perceive that palliative care is all about looking after the elderly or those about to pass on.

Most Malaysians have not heard of palliative care. We are however more aware of homes for the elderly or nursing homes. I think, this is where the misconception is – people tend to associate palliative care with care for the elderly or just nursing care.

What hit me is the fact that serious illnesses such as cancer and organ failure can afflict anyone – young or old. And when it does, palliative care can help! The holistic care encompasses physical, psychological, emotional and spiritual wellbeing of the person - something that makes it unique and is actually a complete area of medicine.

As an adolescent, how did your involvement in palliative care help in creating awareness among people of your age group?

Since the fundraising initiative on my social media platforms, I received messages from people my age, wanting to learn more about HM, about palliative care. To me, this is rewarding as it has piqued interest even among people from my generation. It is important that people, young and old are educated about palliative care, as it has proven to significantly improve the quality of life for those suffering from serious illnesses, providing them a chance to live their remaining life with dignity.

A group of friends and I volunteering at Hospis!

In your opinion, what would be the best way to educate the younger generation on palliative care?

Social media would be the most effective method to spread awareness. A large proportion of what I embrace every day comes from platforms such as Instagram, YouTube and Facebook.

Learning through experience is essential. My own learning journey began when I attended a Volunteer Briefing Session at Hospis Malaysia. The experts provided an insight on palliative care and that alone was life-changing. It also set a quest in me to volunteer at HM. Since then, I remember carving some of the most remarkable memories meeting inspiring individuals who are dealing with these patients every day.

Social media undoubtedly opens the door for many more people to learn and be more aware. As it is now a mode of communication among people globally, it is the easiest, fastest and cheapest way to disseminate information and news. Ultimately though, it is the sharing of stories and experiences that will truly touch one's heart. For many, the patient and caregiver stories we read and hear about online are very powerful and for some, it may be a privilege to witness these stories being told first-hand.

How do you feel about the fund raiser and working with the HM team? Would you consider being part of their other initiatives?


19 June 2021
#RunForPalliativeCare

The experience was awesome! I had reservations but the team at HM were very helpful. They helped with graphics for my SM post, provided a quick and pain free solution to how I was able to track who supported my fund raiser, and promoted me through their platforms. I am truly grateful for their unending support in making this fundraiser a success. I hope that in some way it helps HM achieve their vision and mission. In the meantime, I look forward to being part of HM especially in spreading the word for a noble cause.

FIREFLIES, FIREFLIES, LIGHT MY WAY

Imagine getting lost in a forest without any survival tools. As dusk sets in, darkness surrounds you except for the faint stars that glimmer from trillions of miles away. You feel helpless, lost, and afraid of not being able to make it through the night. “What am I going to do?” you ask yourself. Then, a tiny winged creature lands on your finger. It scares you at first, but then its little bioluminescence light sparkles your eyes with hope. You look around you and see the blinking lights of the fireflies that light up in between the leaves, grass, and trees. The night doesn’t seem so scary after all.

Lighting the way for patients with serious progressive illnesses

This is what it may be like for many patients and their families initially, when they are diagnosed with a serious progressive illnesses such as cancer or organ failure. Often when patients are discharged from hospital, they are sent back to the community with no support. Families struggle to deal not only with the diagnosis of the illness, but also with how to care for their loved one. And if the patient becomes distressed due to his deteriorating condition and worsening symptoms, their caregivers are at a lost, not unlike getting lost in the forest as night falls. A referral to a community palliative care service provider may be the firefly that helps light the way.

Palliative Care is a patient-centred care that focuses on the management of physical and psycho-social pain and other symptoms, with the aim of improving the quality of life of patients living with these serious illnesses. Most patients if given the choice, would prefer for their care to be at home, where they are closer to their loved ones.

Despite the increasing need for palliative care each year, there is still a lack of awareness and understanding of what palliative care is. The thought of being referred to a hospice throws manypatients and families into panic and grief, for it gives the impression that the medical team have given up “hope” and nothing more can be done. Until a community palliative care nurse makes her first visit to the patient at home. Just like a firefly that lands on your finger, these nurses help shine light on the possibility of a quality life despite the illness.

Creating the firefly posse

In April 2021, Hospis Malaysia organized a virtual patient/caregiver feedback session. This is an annual session organized with the aim of obtaining feedback of our services. The session provided valuable insights of what patients and families with serious progressive illnesses experience, and what support they may need to help them through the difficult journey.

Many families described the support provided by Hospis Malaysia as the team that brings together the support structure around the patient - family, caregiver, healthcare providers in hospital and in the community.

In the words of one of the caregivers, Miss Radha, “Bringing our loved one home brings on a bag of uncertainties. If left on our own, we would not be able to cope. The palliative care team works together with their colleagues in hospital, and cares for you and your loved one as you journey through the illness. They will hold our hand through the illness, adding life to days. They are “Angels in the community” that help to relieve your pain and suffering, that guide and support us and our loved ones. They work to ensure our loved one get to live the life they want and deserve. They create the “firefly posse” that brings light to your life despite the darkness that threatens to fall on you”.

Compassionate communities

But what happens then to those who are lost in the darkest of places where there are no fireflies to light up their hope? Currently in Malaysia, more than 100,000 patients require palliative care each year, yet less than ten percent have access to it. A research published by BMJ Supportive & Palliative Care in 2020 estimates that the palliative care needs in Malaysia are projected to increase to more than 200,000 by 2030. The lack of public awareness about palliative care also leads to very late referrals. This means that there is little time for the “fireflies” to gather to help light the path for these patients and their families.

The future of palliative care does not have to be bleak. In the caregiver session, many families talked about the idea of forming compassionate communities. For one firefly would not be enough to light up the entire forest. But if communities step up to advocate for better access to good community palliative care, and neighbours and friends volunteer their time to help the vulnerable, equipping themselves with caregiving knowledge and skills, they could all be the little lights that sparkle in the dark. They could light up each other’s lives, pass on that same hope and be each other’s support.

Perhaps it isn’t necessary to wait for the system to accommodate to our needs the way we cannot close our eyes and hope that the night would turn into the day in a blink. Instead, just like the fireflies, we could all be the light in our community, and help pave the way to help each other journey through the scary uncertainty of living with a serious progressive illness.

Centring on the needs of the patient, a group of caregivers and volunteers could initiate and build its own system of a compassionate community that links families, caregivers and community professionals, so that no one is left behind in this holistic care. Perhaps, we each can be the light that shines on the importance of having a supportive system that cares for its member of the community that is seriously ill or those that are looking after one. The palliative care team has limited time with patients during their visit. In order to extend this care beyond the time that patients and caregivers have with these clinicians, the knowledge of care should also reach anyone and everyone in the community who are willing to volunteer their time and energy.

And darkness need not therefore fall upon patients and their families when faced with a serious illness.