

ASPAC newsletter

January-June 2020 Volume 10



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Our VISION

"DO EVERYTHING FOR LOVE EVEN THE MOST ORDINARY THINGS"

With support from our community, we will provide the best compassionate, competent and loving care to all those who suffer from life-threatening illnesses

EDITORIAL

The COVID-19 pandemic stopped the whole world in its tracks. Life turned upside down, chaos ensued. For the first time ever, people all over the world experienced the same thing, at the same time. With the technology to access real-time information regarding what was happening in different parts of the globe, everyone was kept up-to-date with news on the pandemic.

Currently, our nation is going through a transformational time; combating the Covid-19 threat with a so-called 'soft landing approach' and abiding by a 'new normal'.

As a hospice team, ASPAC has had to navigate choppy waters during the last three months. Right now, we continue to work under restrictive conditions. Visits to homes are still done with caution - wearing some, if not full, PPE (Personal Protective Equipment).

Our cost per visit has gone up and in these difficult times, donations have dwindled. The fund raising dinner event that was to be held in August 2020, has been cancelled. In spite of all the adversities that we are facing, the team continues to work with determination and courage.

The truth of the matter is, any hospice patient who gets hospitalised during these times, will face the prospects of dying alone; without loved ones at their bedside. In order for these patients to continue to stay at home, they will need to have a dedicated hospice home care team to depend on.

ASPAC must survive these hard times to be able to look after all those who need our services but we are in need of funding, therefore, we are appealing for donations.

My request to all who are reading this is, "Please donate generously". If you have the means to do so, please do support us. *No amount is too little. Every ringgit counts.*

If you would like to donate, all relevant information can be found on the donation form at the back of this newsletter.

Thank you.

Dr Lalitha Jeyasingam
Medical Director

**A DIFFICULT TIME CAN BE MORE READILY ENDURED IF WE RETAIN THE
CONVICTION THAT OUR EXISTENCE HOLDS A PURPOSE,
A CAUSE TO PURSUE, A PERSON TO LOVE, A GOAL TO ACHIEVE.**

~ JOHN C. MAXWELL ~

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VISIT TO PPUM'S PAEDIATRIC DAY CARE WARD

By DR TEH EE VON

An event organised by the Hope Matters Team (Business Faculty, Sunway University)

Palliative care, in a nutshell, focuses on improving the quality of life of people with life-limiting illnesses; this means relieving them of suffering. However, oftentimes we forget that laughter and fun is equally important and such an essential aspect of life. On 8th January 2020, on the invitation by a team of Business Faculty students from Sunway University, we joined them in bringing cheer to children at the paediatric day care ward of University Malaya Medical Centre (PPUM).

The kids there, ranging from months-old infants to teenagers, were coming for their usual infusions of medications, blood transfusions and check-ups. The team, called Hope Matters, led by Thaneish Raj, planned out exciting activities to brighten what would normally be a dull, if not difficult, day for these kids.

The star attraction was the clown, who fashioned various items out of balloons for everyone, and entertained even the grown-ups with his tricks. With all the laughter and noise, the only subtle sign that these were not your average kids were the IV cannulas taped to the back of their hands as they fought their hospital buddies with balloon swords.

There was face painting that allowed some of them to transform into superheroes for the day, and henna painting for those who preferred something more subtle. Notebooks and art supplies were also given out freely to encourage them to express themselves in their own time.

Photographers took Polaroid pictures to hand out to the kids and families on the spot so that they



have something to remember the day by. Each child was then given a note from a stash of folded notes that had messages of encouragement written by other students of Sunway University.

The ASPAC team took the opportunity to raise awareness about palliative care and the services we offer; reaching out to parents to tell them that they are not alone in their difficult journey. We are also grateful to Thaneish and team who interviewed us, thus enabling us to spread the awareness of palliative care to a wider audience. This interview will be uploaded onto the *Sedunia* social platform. View it on ASPAC's Facebook page!



Dr Teh and Sr Kris being interviewed by Thaneish.

REFLECTING ON THE DAY SPENT WITH THE ASPAC MEDICAL TEAM

By **TOH SHI KEAT**

A medical student at University Tunku Abdul Rahman

The one-day attachment posting in Assisi Palliative Care (ASPAC), was an eye-opening experience for me. ASPAC is a community palliative care service offered by a team of doctors, nurses, counsellors, and volunteers who visit patients who are terminally ill in their homes. Their role is to help relieve physical symptoms and provide psychosocial and spiritual support to patients and their family members.

During the posting, we visited an obtunded old lady who needed adjustment of morphine doses. She also had a fever according to her daughter. Ms Kong, a nurse in ASPAC did tepid sponging and we were able to observe the process. I learned that we needed to communicate with the patient even when the patient is not fully conscious; as the patient may still be able to hear us. Other than that, we could also communicate not just by talking, but with touch as well. A touch provides comfort to the patient and communicates our care and compassion in a non-

verbal manner. We also learned from Dr Teh, who taught us about drug preparation, drug conversions, as well as the importance of diluting the drug (morphine) for bolus dosing. Ms Kong showed us how to use the portable syringe pump. I realised that this is important to know as it improves our competency as well as our capability to become good doctors.

Next, we went to Sepang to visit a lady with ovarian cancer that had spread to her liver and brain. Upon reaching her residence, we were welcomed by her husband who had taken leave from work to take care of her. Since this was a new case, we took a complete history of her illness mainly from her husband as she was not fully alert and rational. As we were assessing her, we learned that they were originally from Bidor and that they had no choice but to make a decision to move to Sepang because of the inconvenience of getting treatment and lack of family support. Her husband told us that she did not get the anti-

vomiting medicine from the local doctor even when they asked for it. To my surprise, Dr Teh and Ms Kong gave them anti-vomiting and anti-epileptic medication for free before leaving. (Later, I discovered that ASPAC has its own pharmacy and gives out medication free of charge to those who are in need.) The patient's husband attempted to show his gratitude by giving us bottled mineral water to drink.

After lunch, we went to visit a young Malay lady in Sg Long. She was diagnosed with breast carcinoma and had undergone surgery. After assessment, we found out that she did not follow the 4-hour schedule of taking the syrup morphine, mainly due to miscommunication. She seemed to be confused during the counselling which could be due to overdosing of morphine as she told us that on that very morning, she took the syrup 4 times with intervals of 1-2 hours each. She also did not record the timing of morphine usage for the past few days. To overcome this issue, Ms Kong gave her a chart from Monday to Sunday to ease the recording of the morphine intake and reminded her to take it 4 hourly every single day. Dr Teh explained to her that it would be better to hire a care giver since most of the time she was alone in her home, with no one to take care of her. From this visit, I learned that communication is a matter of the utmost importance as it is a central clinical function in building a therapeutic doctor-patient relationship, which is at the heart of medicine. This is very important in the delivery of high-quality health care. Much patient dissatisfaction and many complaints are due to breakdown in the doctor-patient relationship. However, many doctors nowadays tend to overestimate their ability in communication. A doctor's communication and interpersonal skills encompass the ability to gather information in order to facilitate accurate diagnosis, counsel appropriately, give therapeutic instructions, and establish caring relationships with patients. These are the core clinical skills in the practice of medicine, with the ultimate goal of achieving the best outcome and patient satisfaction, which are essential for the effective delivery of health care.

Lastly, we went to Bandar Mahkota Cheras to visit a Malay uncle with underlying diabetes mellitus

and prostate cancer. Ms Kong gave him a can of diabetic milk powder to help with his nutrition as during the last visit, he had complained that he had been taking less amount of food due to decreasing appetite. He was very friendly and appreciative throughout the whole period of assessment and counselling. We also had fun conversing with him. When two people are able to relate to each other, they form a mutual bond and respect which is called rapport. Building successful rapport is the single most important factor in building a relationship. As the key to successful doctor-patient relationships, it is important to know that rapport begins to develop right from the very first conversation the doctor has with the patient. In order to ensure that rapport can be established, the doctor needs to be cautious of how patients perceive him/her by judging not only verbal but also non-verbal communication. I have learned that by demonstrating energy, enthusiasm, respect, empathy, caring, understanding of sensitive intercultural issues from the start, the doctor will be able to begin the rapport-building process, and this, together with competency in communication, represent key skills of medical practice.

All in all, I am so glad as well as grateful to have had this golden opportunity to learn about palliative care by visiting the patients and assessing their conditions with the ASPAC medical team. This will be one of my greatest accomplishments and will definitely be of much help to me in becoming a more efficient doctor in the future.

"To effectively communicate, we must realise that we are all different in the way we perceive the world and use this understanding as a guide to our communication with others."

~ Anthony Robbins ~

MY RESOLVE 2020

By MR SABAPATHY

I have but little wish to be younger.

I dread the increase of infirmities that will make me a burden to those around me, those dear to me.

I am silent about my miseries.

I am indifferent to my present drawbacks and continue to turn my attention away from my own future.

I immerse myself in whatever objective interests that still remain accessible.

I contemplate whatever ideal aspects of existence my philosophy is able to present to me.

I sympathise with other people's overly burdensome affairs but do not allow them to overburden me.

I attempt to cultivate cheerful manners.

I need to practise patience, resignation, trust and tolerance.

Let the end come, let peace come with it.

Let me slip away quickly and as quietly and comfortably as I can; NOW.



ASPAC says...

Mr Saba is a retired surgeon, a cancer survivor and a gentleman with a wry sense of humour. Aging - he is 85 - has not prevented him from learning how to use the computer and internet technology. He describes his desktop unit as "Daisy - his best friend". He writes articles, poems, buys groceries online and spends time surfing the net when he feels up to it. Mr Saba enjoys carving odd pieces of wood into various objects / shapes. Many hours of dedicated work went into fashioning the shark in the picture above.

He has formed a strong friendship with his hospice nurse, whom he calls his "granddaughter"!

COVID-19: CHANGING THE WAY WE WORK

The COVID-19 pandemic has impacted all of us; in the way we interact with each other right down to how we do our jobs. Here in this photo, we have two of ASPAC's medical staff listening in on a WhatsApp video call as our grief counsellor, Sr Kris, talks to the daughter of a patient who is afraid of death and worried about evil spirits.



Sr Kris explored the situation with the daughter and suggested ways of helping her mother to come to terms with death and letting go. The daughter was tearful during the conversation but relieved to be able to talk to Sr Kris about her concerns. We assured her that we would provide phone call support anytime she needed it. Several home visits were also made by staff during the period of the MCO when it was apparent that the patient needed review and assessment of her physical condition.



Visiting patients at home during the MCO is tedious and physically uncomfortable. The PPE (personal protective equipment) makes one break out in perspiration and the tight fitting masks are uncomfortable to breathe in but necessary.

This elderly patient has advanced head and neck cancer and neuropathic pain due to a fungating cauliflower like growth on the side of her neck. She is slowly deteriorating at home but is well-supported by a loving family. The visit was made to reassess the patient's symptoms and to titrate the medications.

◁ *This patient always wants to hold our hands, and show us her love for us, whenever we visit.*

At the beginning of the COVID-19 pandemic, it was very difficult to get proper PPE (personal protective equipment) for staff to use whilst visiting patients at home. We had to improvise in all sorts of ways. Using garbage bags as shoe covers, raincoats as isolation gowns ... these were some of the things we used to cope with the situation we faced.

Nurse Satwin in improvised PPE at the beginning of the pandemic; when we could not obtain proper protective suits yet needed to visit the patients. ▷



EMPOWERING CARE-GIVERS

The patient, Mr Lim Phaik Khoon, was a lovely gentleman who suffered from advanced lung cancer. Throughout the time we looked after him, he would try to laugh and joke and keep things as normal as possible even when he was uncomfortable or ill. He looked forward to visits from the hospice team and would regale us with 'horror' stories of the times he was hospitalised. He was determined to stay at home till the end of his life. During the last few days, he could not swallow his medications and was switched to analgesics that were in patch form (for application on the skin) and also via a syringe driver (subcutaneous infusion of medicines).

Nurse Roohini teaching the carer, (wife of the patient), how to use a fentanyl patch and apply it on the patient's skin for pain control. ▷



NEW HORIZONS AT ASPAC...

By **GILLIAN FERNANDO**

I began my career at ASPAC as an Administrative Clerk. Before coming into this position, I had not been working for about 3 months. I was very thankful to ASPAC for taking a chance on me although I was from a different background of study; I have a degree in Geology.

As an admin clerk, my job was to answer phone calls and take messages and to pass them to the relevant persons. The challenge for me was to learn about the medical equipment so that I could teach patients' families how to use them. Not coming from a medical background, I had to learn how to operate the medical equipment, such as the oxygen concentrator and nebulizer. Besides that, I had to also keep a record of the incoming and outgoing equipment. As I went along, I learnt more about the medical equipment from our experienced staff.

After my superior left, I took over some of his tasks. I left the receptionist table to our faithful Ms Yap;

only occasionally answering incoming phone calls and taking messages.

My job now is more administrative orientated and my responsibilities have grown.

I am now helping with the compilation of data for reports; a job scope that I am familiar with, but only with a different type of data.

I also work with the team to compile documents for applications such as grants.

In addition, I am also responsible for verifying documents related to staff claims before they are approved by the Medical Director.

I am blessed to work with a great team. This job has really broadened my horizons and has also opened my eyes to the pain people go through when struck with life-limiting illnesses. This has made me appreciate my life even more.

THANK YOU FOR YOUR DONATION...

SMJK SHING CHUNG (SUNGAI SIPUT) - CLASS OF 1998 -

Having read about ASPAC's work on the internet, SMJK Shing Chung's (Sungai Siput) alumni, made up of graduates from the Class of 1998, took up a collection to raise funds for ASPAC. The donation was handed over by the alumni's representative, Ms Bennie Chew to our Administrative Officer, Gillian.

We would like to extend our appreciation and thanks to the graduates from the Class of 1998 of SMJK Shing Chung (Sungai Siput) for their kind donation.



Gillian and Ms Bennie Chew (right) with the mock cheque.



SOROPTIMIST INTERNATIONAL (BANGSAR)

The members of Soroptimist International (Bangsar) donated personal protective equipment (PPE) such as coveralls, isolation gowns, masks and shoe covers.

We, at ASPAC, would like to record our sincere appreciation and gratitude for this donation.

WEAVE FOR CHARITY

Kate, a weaving enthusiast from Weave.Fun MidValley Megamall, had set up a booth within the mall last Christmas period, calling it – Weave for Charity. Through her commitment and efforts, and the participation of the enthusiastic staff at MidValley Megamall, her booth managed to collect and channel RM15,000 in donations to ASPAC.

Staff members of Mega Mall Corporation visited ASPAC in January to hand over the cheque in a simple ceremony. All of us at ASPAC are very grateful indeed for your kind hearts and wonderful generosity!



Kate (left) showing a customer some of the woven goods at her stall.

YAYASAN SIN CHEW

Thank you, Yayasan Sin Chew, for standing by ASPAC and donating so generously to us. Benefactors like you help us to continue our services to those in the community who are in desperate need of help during the last stage of their illnesses.

ASPAC Board members, Mr Phoon Soon Keong and Mdm Ho Sook Harn (Mrs Wong) receiving the cheque on behalf of ASPAC. ▶



CHEERING UP OUR PATIENTS IS ALSO A PART OF WHAT WE DO...



ASPAC volunteers visiting a nine-year-old patient at his home to brighten his day.

His Mom (in yellow T-shirt) looks on with a smile.

Carollers from the Church of Our Lady of Fatima, Brickfields took the time to visit patients along with ASPAC staff and brought cheers and smiles.

ASPAC Volunteer, Mario brought along his golden retriever, Arthur - our pet therapy mascot - as well!



A MESSAGE OF THANKS...

From the Late Mr Krishnan & Family

Mr Krishnamoorthy Narayanan – the patient – wrote this himself and instructed his daughter, Chandra, to rewrite the message in a thank you card which was delivered to ASPAC along with beautiful flowers; in appreciation of the ASPAC staff members.

He was referred to us during the MCO and had received one home visit where staff went in PPE to see him. Subsequently, the patient and family were supported via video calls and they used the on-call emergency phone line when they needed help. Mr Krishnan passed away recently.

Call Dr Teh to thank her and her wonderful team for their genuine Love, Care and concern ~~for~~ ⁱⁿ organizing for my Dad to receive the best treatment available. Kindly forgive us for calling you at odd times to arrange last ^{minute} ~~moment~~ ^{admission} knowing ~~it was~~ ^{very well that it was} ~~our~~ ^{not} our fault for pushing you ~~very~~ ^{hard} till a place was confirmed by your tireless efforts. Please accept our sincere apologies. We are yearning to ^{meet} you again at your convenience. ^{of your} ~~your~~ ^{loving} team, God Bless you ^{Dr Teh} and ~~Dr Teh~~.



From Ms Leanne Ooi

My Dad and I were referred to ASPAC when PPUM decided that my late Mom, a 72-year-old, bed-ridden, stroke patient (a result of a brain tumour operated on in 1984) should be moved towards palliative (end of life) care. The PPUM team felt they could no longer treat her and we agreed with her doctors; taking her home was the best option and what Mom would have wanted. At this stage, she was unable to speak and needed round-the-clock care.



An old photo that brings back happy memories for Leanne. She is with her Mom and sister in this photo.

It is difficult to watch one's closest and dearest to us suffer and we were constantly anxious if we were doing enough to ensure she had the best care and was as comfortable as possible.

In the last 6 weeks of Mom's life, also the most challenging period for the family, Dr Lalitha and her team were constantly in touch with us. They made sure we were supported emotionally. They spoke to my 3 children, her grandchildren aged 14, 11 and 9 to ensure they understood and could cope with seeing their grandmother being so ill and made sure we were clear about the options we had and what outcomes to expect. They visited my Mom at home a few times a week to ensure she was not in pain and helped us with feeding decisions and the administration of medication.

It made a huge difference in how we managed Mom's care and I am forever grateful to the brilliant care and support which was provided.

FUNDRAISING INITIATIVE: DECOUPAGE JUTE BAGS

By **MARIA LEE**

A group of senior citizens from Bandar Utama got together to make decoupage jute bags to raise funds for ASPAC. They spent about 5 months making them and sold about 350 bags through their network of friends.

Their efforts raised about RM14,000 for ASPAC. They are happy to have this opportunity to give back to society. In addition, this project created a bonding time for them and they became good friends.

This is an ongoing ASPAC project. These bags make lovely corporate gifts, Mother's Day gifts, etc. Anyone interested in ordering the bags may contact Maria Lee at 019-6735708.



DONATIONS ARE APPRECIATED!

Be A Friend of ASPAC

*We depend entirely on the generous hearts of benefactors to sustain us financially.
Please help us help others. Be a Friend of ASPAC.*

Name: _____

Address: _____

Mobile: _____ Email: _____

Please accept my contribution of: RM _____

A. By cheque attached (No. _____)

Please make cheque payable to **ASSISI PALLIATIVE CARE BHD**

Cheque to be posted to 49, Jalan Railway 1/2, 46000 Petaling Jaya, Selangor.

B. Via direct remittance to ASSISI PALLIATIVE CARE BHD - (Public Bank A/C No: **3-1968057-28**)

To receive an Official Receipt, please fax or scan the bank-in slip or IBG transaction receipt to

Fax No. 03-77838899 or Email: info@aspac.my

with details such as name of donor and mailing address.