



# ASPAC NEWS

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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.

## Our MISSION

To empower people to live with dignity and hope whilst coping with illness and loss by providing quality medical care, spiritual and psychosocial support to patients and their families.

## Our CORE VALUES

Honour and Respect the wishes of our patients

Excellence of care

To always serve with Compassion and Love

# EDITORIAL

Spirituality ...**"is a way of being"** *Elkins et al.1998 J.Humanistic Psych, 28(4):10* and characterised by how one relates to one's own Self, others, Nature, Life, the Universe or Ultimate being/Self/God.

It is an important component of QOL (Quality Of Life) and can be a key factor in how people cope with illness and experience healing. Spiritual care is an essential domain of palliative care (the others being Symptom management, Psychological and Social Care). We are all spiritual beings having a human experience on this planet Earth.

The diagnosis of a life-threatening illness often results in the person reflecting on the meaning of life which leads to suffering and spiritual distress. Suffering is a complex human experience. A patient's belief system affects the meaning they give to their suffering. The patient's belief system must be respected. Without understanding the patient's beliefs and values, the hospice team cannot engage in shared decision-making with the patient and family.

At ASPAC the team will check with the patient and family regarding religious, spiritual and existential concerns using structured questions and we integrate this information into the Care Plan. We live in Malaysia which is multicultural and where many different faiths

are practised. However, we often meet patients who consider that religion is one way to express spirituality but it is not the only way. We use the patient's personal goals as a point to work towards, accepting that the patient's goals are often quite different from what we may expect. The staff are trained to accompany the patient as they struggle to find satisfactory answers to questions about the meaning of Life, illness and the mystery of death. Even if the situation cannot be changed, it may be possible to change the meaning the patient gives to it. Sometimes our role is simply to create a safe space for the expression of this suffering and for exploration regarding its meaning, without any judgement .

We have links with various members of different religious organisations so that we can quickly obtain help for those patients who wish for specific spiritual or religious care from a priest, a monk or an imam –should it be required.

The home care team does work with patients that can be emotionally draining and sometimes physically exhausting. It often demands for a work ethos that goes beyond the call of duty. I take this opportunity to salute all members of the team...each one of you gives so much of yourself unstintingly to these patients we look after. Syabas and may God bless you all richly.

*Dr Lalitha Jeyasingam*

## NEW STAFF

### SOONG MEE CHAN



Ms Soong Mee Chan joined us recently and has been tasked to manage the pharmacy in ASPAC. She was a dispenser in Assunta Hospital, Petaling Jaya for the past 40 years, therefore she has a wealth of experience in this area.

### GILLIAN FERNANDO



Ms Gillian Fernando commenced work as Administrative Assistant from July 2018 taking over from Patricia Nilsson. She holds a degree in Geology but after six years in the industry decided to try her hand at something new.

#### Editorial Team

Dr Lalitha Jeyasingam  
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# BeCause DURIAN CHARITY 2018

An "Eat All The Durians You Can In One Hour" event on 15<sup>th</sup> July was organised by BeCause to raise funds for ASPAC as well as for a welfare home for orphaned/neglected children and abandoned old folks in Cheras. BeCause is a social initiative by the Community Care Society of Malaysia situated in Petaling Jaya and is a registered NGO. The event ran over three hours and was started off by a drum session performance by some students.



Eating durians unites Malaysians!

It garnered immense support from Malaysians of all walks of life who willingly surrendered their money to eat unlimited amounts of the king of fruits and also to give to a good cause. BeCause managed to raise RM90,000 from the Durian Charity 2018 event and the amount collected was split equally between ASPAC and Bodhi Homecare.



Mrs Wong, Board member of ASPAC (2<sup>nd</sup> from right) receiving the cheque for RM45,000

A big thank you to BeCause! We are truly grateful for your support and generosity in helping to fund our palliative home-care programme.

## EXISTENTIAL-HUMANISTIC PSYCHOLOGY CONFERENCE 2018

The palliative care team attended The International Conference on Existential-Humanistic Psychology 2018 which was held at HELP University Subang 2 on 21<sup>st</sup> and 22<sup>nd</sup> July 2018. Existentialism and death are related and intertwined. Addressing death and the issues that arise from death in therapy is a topic that is welcomed by some and avoided by others.

We spent two days listening to experts in the field - Malaysian Psychologists (Dr Anusuya J, Frederick Boholst & Evone Phoo) and several international speakers (Paul McQuillan, Scott Churchill & Mark Yang) - discuss subjects like *Existential Shattering, Overcoming Grief and Loss with Mindfulness, Finding Meaning with Logotherapy*, etc.

**LOGOTHERAPY**

Form of psychotherapy focused on helping patients find meaning in life in 3 ways:-

- > Work and hobbies
- > Experiencing life & people (love)
- > Developing a positive attitude!

The diagram is a triangle with three blue circular nodes at its vertices. The top node is labeled "Attitude Change", the bottom-left node is labeled "Creativity", and the bottom-right node is labeled "Experience". Lines connect the nodes to form the triangle.

Viktor Frankl the founder of logotherapy published the 'Unheard Cry for Meaning' 40 years ago in response to what he perceived as a "growing sense of meaningless" worldwide. He suggested that logotherapy in conjunction with

other therapeutic approaches was needed to address this deepest of human needs to find meaning in life. Logotherapy showcases the defiant power of the human spirit.



*ASPAC staff attending a talk at the EHP Conference.*

**Who will I be then? ...** The phenomenological reflections on coping with trauma, loss and grief by Scott D Churchill, reframing life's challenges can liberate us from despair and help us to find a way of moving forward. Our responses are not determined by the situations that give rise to them, it is the freedom to choose our attitude in any given set of circumstances.

There were several workshops conducted during the 2 days and we came away with an enhanced perspective of all that it takes to deal with the spiritual and emotional aspects of grief, loss, death and trauma.

## 13<sup>TH</sup> MALAYSIAN HOSPICE CONFERENCE

The 13<sup>th</sup> Malaysian Hospice Conference was held in Alor Star, Kedah on 28<sup>th</sup> July and was attended by over three hundred delegates from all over Malaysia. ASPAC was represented by two Board members and four staff at the conference.

There were talks by local and overseas speakers in the likes of Professor Ghauri Agrawal and Frank Brennan - from Sydney, Australia - who discussed controversial issues like physician assisted suicide (illegal in Malaysia, but legalised in certain states in Australia, America, etc) which could lead to an increased number of terminally ill people requesting for assisted suicide in the future if they felt that they would be a burden to family and society.

A workshop on mindfulness in palliative care was conducted by Professor Dr Tan Seng Beng and Dr Loh Ee Chin.

A gala dinner saw many delegates in their evening best mingling and enjoying the occasion.

The Malaysian Hospice Council also held their Biennial General Meeting during this time where Dr Lam Chee Loong (Senior Palliative Care Consultant, UMMC) was elected to take the helm as MHC Chairman. Congratulations to Dr Lam and we look forward to better things ahead in the next two years.



*L-R: Dr Patricia Por, Mrs Wong, Dr Teh, Nurse Satwin, Nurse Roohini & Dr Lalitha*



*One of the workshops in session.*

# Rule 1: Have the time of your life.

## Rule 2: Don't forget Rule #1.

This was the heading of the card I received after Mummy had passed away. Mummy had prepared letters for each of her children and their spouses in the month before she left us. It was a culmination of a life well lived which had inspired all around her.

It was a time of knowing and yet not of knowing. We were facing a situation in which we knew the end and yet did not know the journey. There were more questions than there were answers. And those questions would only be answered slowly and painfully, in bits and pieces as we walked together through Mummy's last days.

Mummy survived breast cancer for 7 years. It was the urinary bladder cancer diagnosed in April 2011 that would be a constant battle. Mummy went through surgery and chemotherapy a few times. Every four months, we would dread the journey to the hospital for another round of scope under general anaesthesia. The after-effects were difficult to bear to say the least. Yet, in the 7 years, she lived as normally as possible with the love and support of her family and friends. She travelled often and had a wide circle of friends. Her greatest joy were her grandchildren. She would take every opportunity to fly to Sarawak to visit them laden with gifts.

In January 2018, when a nagging backache grew worse despite medication, we were worried. Ultrasound of her abdomen revealed extensive lymph node metastasis of the abdomen. Her bladder cancer had now migrated to her right kidney. Further investigations found that she also had metastasis to her left hip joint.

During this trying session, I was very quiet and tried to keep a calm demeanour as I viewed the extent of the metastasis on the ultrasound screen. Mummy looked at me intently and I could not meet her gaze. We drove home quietly and as Mummy went to her room to change, I sat

down and stared at the words of the radiology report. Tears could not help pouring out



even as I fought hard to keep my composure. I immediately informed my brother and husband and my mother's oncologist. When Mummy came out of her room, she knew from my bent head looking at the document in my hands that the news was not good. She came towards me and hugged me and comforted me. She said "We all have to go some day".

I told Mummy her surgical options - all of which she firmly rejected. She was prepared to leave this world, she said. I believed her and told her that as her immediate family, we would support whatever decision she made for her life and would be with her till the end.

We prepared ourselves to inform her family and we discussed how we should go about this process – preparing ourselves for the grief the news would bring.

After that, we contacted ASPAC and we had our first visit at the end of January by Sister Kris, Nurse Satwin and Dr Lalitha. That first session was very good for us because we knew we had support and felt that they genuinely cared for our wellbeing. We went through "end of life care" which was very difficult yet needed to be brought out to the open. Mummy was not keen on any intervention except for a morphine infusion whenever she was ready to request for it.

We were determined to continue our routine as normally as possible. At the same time, we tried to prepare as best as we could to make Mummy more comfortable. New furniture was bought to make her bedroom more conducive for visitors to sit with her in her room – and we knew she would have many as she was much loved. I had

hoped that my mother would be able to be mobile and active as much as possible though I knew that would be tough with the bone metastasis.

Every 3 weeks we noted a downward trend in her ability to be independent. From a walking stick, she needed a walker. From bathing on her own, she now needed assistance. She could not change herself and her appetite decreased. She needed to be fed. Her need for more pain medication increased.

Mummy was a fiercely independent person who had overcome many obstacles in her life. Her determination for her children's future was her life's goal. She led the exercise group in our neighbourhood and would drive around everywhere by herself. Oftentimes, our plea that she drive slower fell on deaf ears. She inspired the women living around us with her energy and smiles.

The most difficult times were the nights when Mummy would go through unbearable waves of spasmodic pain. She was more concerned for my rest than for her own suffering that she would make her way to her armchair while I slept and would sit in the darkness with the television on softly so as not to wake me. One night as she tried to get up from her seat to make her way into the kitchen, the soft tapping of her walker caused me to jump out of my bed. I made her sit down and quickly went to prepare whatever it was she needed. It was 2 o'clock in the morning and Hamlet was showing on television. I sat up with her. She had so many questions. It was difficult for me to accept that she was now forgetful and confused. She had known Hamlet almost by heart – having studied Hamlet for her school leaving certificate. She loved Shakespeare and had introduced me to his writings when I was young. And there we were, in the dark with me trying to explain Hamlet while waiting for the pain medication to take its desired effect.

We would laugh and joke with Nurse Satwin and Sister Kris that we knew all the world's breaking news while the rest of Malaysia slept. Our roles had reversed. When I was a baby, Mummy would stay awake with me through many childhood illnesses. Now Mummy was my baby.

In early March, we started on opioid patch and aqueous morphine with a cocktail of stronger painkillers. Mummy was in almost constant pain. She was very strong and had a high pain threshold. When her grandchildren came to visit, she would bear with the pain so that she could spend every minute being with them. It was only when they left to go out for an outing, did she reveal how much pain she was in. She did not want to be sleeping while she could still interact with her grandchildren. Time was precious.



*The late Madam Clara with Nurse Roohini and Sister Kristin*

Three weeks later, Mummy was bed bound. I could not sleep that night. She had almost fallen twice because her left leg could no longer support her even with her using a walker. I knew that this was the beginning of the last days for Mummy. I spoke to her in the morning that it was best for her to be bed bound. I explained my fear of her fracturing her leg – a scenario that I could not bring myself to contemplate. But I would leave the decision to her. I supported her as she tried to walk with her walker. She buckled after a few steps. And we knew that she would not be able to walk again. Neighbours came immediately that early Saturday morning to move furniture and help her get comfortable. The church which had been a source of encouragement to us all through the 7 years, was now the pillar on which we leaned.

Friends and family were a source of strength for us, too. Everyone did all they could for us. From running errands, going to the pharmacy, sending food to us and singing songs. From the early days of tears and grief, our home was now a place of contentment and life. Grandchildren played around her bed which was now in the living

room, cautious only around the morphine infusion pump. We knew we were much loved.

Soon after Mummy became bed bound, I hired a nurse called April. She was very good with Mummy and they would while their time away with gossip and watching Korean drama. This freed me to run errands and more importantly, to rest.

Mummy was resolute in her decision to not seek further treatment or have a feeding tube or an intravenous line. She agreed to a urinary catheter to make our lives easier. She always put others before herself. She made detailed funeral arrangements on her own directly with the Nirvana funeral director. This was a new experience for him and a testimony of faith that Mummy possessed. She testified that death was not to be feared but to be accepted when it was time. I knew then that Mummy would fade away peacefully and I was comforted.

We went through a roller coaster of emotions as the days passed with a daily deterioration of her condition. We cried together many mornings as I lay my head on her chest and she would kiss me gently murmuring “my darling daughter”. In private, I broke down frequently. I could hardly utter a sentence without crying during a hospice visit. I am grateful for the relationship we had built with the team that allowed me to express myself freely. April had grown very fond of Mummy and admired her strength and courage. We cried together many times as we were faced with the challenges of pain control. We would cry in despair as we felt we were chasing the wind and grasping at straws.

After another family discussion, we requested the hospice to start morphine infusion. We explained to Mummy and she nodded her agreement. She was more comfortable after that and slept through the nights. We slowly increased the dose of morphine as her need for comfort grew. She had stopped eating. She took sips of fluids to wet her lips and tongue. We continued to massage her with her favourite massage oil and never forgot to spray her with White Linen perfume. Her last smile was when my husband, Karam

suggested we paint her toenails red and she nodded in happiness and her eyes shone bright.

Mummy passed away peacefully on 22<sup>nd</sup> April 2018 surrounded by her grandchildren kissing her and holding her, her children and their spouses, her eldest sister, Violet and nurse, April. The last words she heard were “we love you”.

*by Dr Carmen*



*A life well lived is a precious gift of hope  
and strength and grace,  
It is filled with moments sweet and sad,  
With smiles and sometimes tears,  
With friendships formed and good times  
shared,  
And laughter throughout the years.  
God saw you getting tired when a cure  
could not be;  
So He wrapped His arms around you,  
And whispered – Come to Me.  
You didn't deserve what you went through  
And so He gave you rest,  
It was for your best.  
When I saw you sleeping so peaceful and  
free  
From all your suffering and pain,  
I thank God knowing, we will surely meet  
again.*

*by Mrs Ethel Christie Melvin  
(Clara's youngest sister.)*

# ASPAC FUNDRAISING DINNER 2018

ASPAC's Annual Fund Raising Dinner was held on 11<sup>th</sup> August which saw five hundred people attending a sumptuous dinner at the Extra Super Tanker Restaurant located in Glo Damansara. The owners of the restaurant, Mr & Mrs Lam and family generously sponsored the sumptuous meal. There was music to entertain the diners, a short video presentation regarding ASPAC and an opening speech by Dr Patricia Por (Chairperson of ASPAC). Mrs Pat Lam spoke

about her mother, the late Madam Teresa Chan, who was looked after by ASPAC during the last stage of her illness. She was a wonderful lady who was always smiling and ever hospitable to the staff who attended to her.

## **Summary of Mrs Pat Lam's speech...**

*Mrs Pat Lam expressed her gratitude for the opportunity given to her and her husband to host the charity dinner in memory of Mrs Lam's mother, the late Madam Teresa Chan. In line with the dinner's theme of 'With gratitude for life and service' it also gave her an opportunity to thank Assisi Palliative Care "who walked with me and mom, in the last two years of her life", especially the palliative doctor, Sister Mary Kristin and Sister Emelda.*



*Mrs Lam's mother was in her eighties and suffering from dementia but a "happy dementia and very childlike in behaviour" in Mrs Lam's own words. However, in 2014 when at the age of 86 years, she was diagnosed with stomach and colon cancer. Mrs Lam and*

*her siblings were overcome with disbelief, fear and anger at the diagnosis but as they calmed down and gathered their thoughts, they began to weigh their options carefully. Given the late Madam Chan's condition and prognosis, the five siblings ultimately settled for palliative care.*

*Madam Chan was soon registered as a patient with ASPAC. The attending palliative doctor at that time together with Sister Mary Kristin, addressed all their queries and fears professionally and compassionately;*



*Mrs Pat Lam and ASPAC Volunteers*

*explaining carefully the issues that may arise, the options available, the processes involved and how to handle things one step at a time. The medical team's visits evolved from monthly, to fortnightly, to weekly and then to visits and phone calls as and when help was required. Being informed and educated as time progressed had kept the family calm and balanced. Their presence was very reassuring to Mrs Lam as it must have been for her mother too.*

*Madam Chan passed away in April 2016 without suffering a single day of pain. She was mobile, ate well by herself, slept well and was her usual smiling and happy self till the end.*

*Based on her own experience, Mrs Lam saw that palliative care could be an option for quality of life for people who are seriously ill. Besides that, it also addresses the emotional needs of the family which is more important than one realises; as it is a difficult time for everyone and the family too needs support.*

*Mrs Lam pointed out that ASPAC's services are free. Therefore she encouraged everyone to share with family and friends the work done by ASPAC and to offer support be it in money, in time or in kind.*

*Lastly, on behalf of ASPAC, Mrs Lam thanked all the doctors, nurses and people of goodwill who have contributed their time and money. She also expressed her gratitude to the many volunteers who worked hard behind the scenes to raise public awareness regarding ASPAC.*

# INDONESIAN MEDICAL STUDENTS' ATTACHMENT AT ASPAC

Six medical students from ATMA Shanti Catholic University, Indonesia did an attachment posting with ASPAC on 16<sup>th</sup> August 2018.

They attended the clinical progress review of patients in the morning followed by a teaching session on effective communication. They also participated in a role play after which they went out with the team to see patients at home.



## AN EVENING SHOWCASE OF PRAISE 2018

On 1<sup>st</sup> September, An Evening Showcase of Praise (AESOP) was held at the Drum Asia Studio in Sri Hartamas. Just a few months earlier, the organisers Tishay de Rozario and Damian Emmanuel had come up with the idea of having a musical showcase for charity. They had wanted to give credit to the fact that their



L-R: Ruben (Volunteer), Dr Por, Ms Yap (Volunteer) and Nurse Kong

musical journey had largely begun in their own churches, and they decided on a show that would be based on Christian

praise and worship. One phone call led to another, and soon an ensemble of 9 musicians from different churches of different denominations came together. Bonded by their love for music and their beliefs, they made magic.

ASPAC was fortunate enough to have been chosen to be the beneficiary of the event, and we were also invited to set up a booth there to spread awareness of our services. The crowd was attentive as we spoke of palliative care and what we do, and many were touched that this kind of support is possible. The musical showcase managed to collect RM5,500 in total for ASPAC.

Our heartfelt thanks to the AESOP organising committee for this opportunity!

*The musicians involved were:*

*Keyboard/Music Director: Gabriel Januarius*

*Electric Guitar: Jeremy Kong*

*Bass: Joseph Steven*

*Drums: Rebecca Cheah*

*Percussions: Stan Calvin*

*Vocals/Acoustic Guitar: Jayvine Ramma*

*Vocals: Charleen Manuel*

*Vocals: Kenneth D'Cruz*

*Vocals: Kathleen Gomez*



Tishay with his late grandfather who was looked after by ASPAC

# ASPAC MEMORIAL DAY

On 13<sup>th</sup> October, ASPAC held a memorial service for the families and loved ones of our patients who have passed on in the previous year. We hold this gathering every year to give them an opportunity to honour the memories of their loved ones, and to give them a sacred space to remember and reflect upon their journey.

This year, 78 people attended the service, some even travelling from out of the country just for the occasion. The service was opened with the lighting of the candles to signify light within the darkness of grief, followed by multi-faith prayers. Then there was a video with pictures of those we had loved and lost. Next, some family members were given the time to share their experiences,



which they were grateful for because it gave them an opportunity to talk about their loss in a safe environment. It was a solemn event that included flower tributes and candle lighting, culminating with the release of balloons that had each person's personal message tied to it.

The loss of a loved one can wound deeply, but it also means that we had dared to love greatly. And that is, ultimately, what being human is all about. We at AsPaC are honoured to have been allowed to journey with these families through one of the most trying times of their lives, and for that, we thank you.



# SELF-CARE WORKSHOP



*Creating self-awareness*

A full day Self-care Workshop was held for the ASPAC staff and conducted by Ms Thang Mee Yuen on 6<sup>th</sup> October 2018. Those of us who work in palliative care are at high risk for compassion fatigue and burnout. It can be stressful to work with patients who have serious illnesses and deal with end of life issues, death and dying.



*Group session via Art Therapy*

Ms Thang is a clinical psychologist with many years of experience in the field of palliative care. She spent the day with the ASPAC staff teaching them self-care strategies and coping methods in seemingly 'fun' ways ... which on reflection made us more self-aware and conscious of the importance of looking after our emotional wellbeing.

ASPAC will conduct programmes on a regular basis in 2019 as part of strategies to manage stress and support the staff within the organisation.

## VOLUNTEER TRAINING PROGRAMME III

The Volunteer Training Programme III was conducted at ASPAC on 3<sup>rd</sup> November from 9 am to 4 pm.

Some of the training material included *'How to handle emergencies in a home care setting', 'Communication Techniques, Role Plays, Self-care and Volunteer Guidelines'*.

The next volunteer training programme will be held in January 2019. Please check the ASPAC website / FB page for details!



*Participants doing small group work.*



*Learning through role play.*

# VOLUNTEERING AT ASPAC



My name is Kamala. I am a volunteer for ASPAC. I started working with ASPAC in 2015. I became a volunteer to help in the activities and to visit patients.

I attended a few trainings before I began going out with the nurses. I have learnt that there is a lot more sufferings out in the world than we actually know. This has taught me to appreciate every little thing that I have and am able to do. Simple things like being able to get on my feet and brush my teeth and do things that I wish to do.

Each time we volunteers visit the patients, they are very happy to see us visit them. We do hand massage and talk to the families or caregivers who are also very tired out.

I continue doing it because it gives me a lot of satisfaction and to let my children and others know that giving some of our time to this cause is a good way of getting satisfaction. I hope to be an example to the future generation.

*by Kamalasanil Thilagalingam*

**WHEN YOU DO THINGS  
FROM YOUR SOUL,  
YOU FEEL A RIVER  
MOVING IN YOU,  
A JOY.**

**RUMI**

## 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](mailto:info@aspac.my)*

*with details such as name of donor and mailing address.*