



ASPAC NEWS

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Volume 6

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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

Greetings and Selamat Hari Raya to all our Muslim friends! It is three years since we rolled out the first volume of ASPAC NEWS. For those of you who are not familiar with our organisation, ASPAC (Assisi Palliative Care Bhd) was started in July 2015 and is a company limited by guarantee and not having a share capital. We encountered many challenges when we first started. However, after 3 years of steady work we now have a reliable palliative care team that includes 5 nurses, 2 doctors, a counsellor and a dispenser together with a loyal band of volunteers. We have 2 administrative staff who gallantly multitask to run the office efficiently on a day-to-day basis.

The number of referrals we receive from public and private hospitals has been steadily increasing. 90% of the patients have advanced cancer. Two-thirds of our patients are more than 60 years of age indicative of the increasing aging population in Malaysia.

We have a core group of senior volunteers who carry out various duties such as Touch Therapy, sitting with patients to give the carers respite, holding vigil for patients at the End Of Life, driving patients to attend hospital appointments, grocery shopping etc.

We conduct training programs in basic palliative care for the public, volunteers and health care

workers. Activities are posted on the ASPAC Facebook page and on our website. We are committed to continuous professional development; we strive to give members of our staff opportunities to gain post-graduate qualifications in palliative care as this will help ensure that we excel in giving high quality care to all our patients. Medical equipment (eg hospital beds/oxygen concentrators/wheelchairs, etc) is loaned out FOC and medicines are supplied whenever possible. We have the capability to set up infusion pumps at home if there is a necessity. We deliver care to the patients in their own homes and our aim is to **serve all with compassion, respect and love.**

I hope Volume 6 of ASPAC NEWS will give you insight into our various activities and maybe spur you into signing on to become a volunteer! Feel free to email me at info@aspac.my should you have any comments/queries or wish to contribute interesting articles. Thank you.

Dr Lalitha Jeyasingam
Medical Director

“Compassion is sometimes the fatal capacity for feeling what it is like to live inside somebody else’s skin. It is the knowledge that there can never really be any peace and joy for me until there is peace and joy finally for you too...”
~ Frederick Buechner ~

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MASP 6TH BIENNIAL SCIENTIFIC MEETING AT IKN, PUTRAJAYA

The doctors and nurses of ASPAC attended the 6th Biennial Scientific Meeting of the Malaysian Association for the Study of Pain 2018 which was held at the National Cancer Institute (IKN), Putrajaya on 17th and 18th March 2018. The theme was *'Delivering Better Relief for Cancer Pain'*. Doctors and Allied Health professionals from many specialities attended and there were a number of participants from the various hospices in Malaysia.

There were interesting talks from overseas speakers like Prof Andrew Rice from the UK (*Assessment and Treatment of the Patient with Neuropathic Pain*) and Prof Richard Chye from Australia (*Assessment and Treatment of Breakthrough Pain with Rapid Onset Opioids*). We had several good local speakers as well like Ms Thang Mee Yuen from the Paediatric Institute of Hospital Kuala Lumpur (HKL) who shared her experience and knowledge of Expressive Art

Therapy for children with cancer. Dato Dr GL Kuan spoke on the prevalent culture towards children with cancer pain in Malaysia and she highlighted the fact that long term traumatic memories have been reported by children receiving painful medical procedures, more so in paediatric oncology patients.

Continuous professional development is important for the palliative care team to upskill itself. ASPAC requires its staff to keep updating themselves and acquiring knowledge of the latest developments in the field so that we can better serve our patients in the community.

Attendance at the meeting was also an opportunity to meet old friends, network with other organisations and share information which could help make our work in the field more efficient.

by Dr Lalitha Jeyasingam



ASPAC nurses and doctors at the MASP scientific meeting in IKN, Putrajaya.

Front (L to R): Kong Kam Yong, Dr Teh Ee Von, Roohini, Masita, Satwin Kaur.

Back (L to R): Dr Lalitha J & Senior PCN Ong Swee Ee



Chatting during coffee break!

Nurse Kam Yong with nurses from Hospis Seremban.

L to R: Lim Cheok Hong, Norzila Yaakub, Elizabeth Pereira, Jennifer Engkas, Kong Kam Yong

JOURNEY OF A HOSPICE NURSE: HELPING DYING PATIENTS LIVE OUT THEIR LAST DAYS IN PEACE



The first emotional milestone I encountered was the sorrow of my patients and the tremendous grief expressed by their families. I soon understood that I could not bear this load by myself, as the sadness

was too great. Nurses cope in different ways to what are often tremendous job stresses. My main coping strategy is my daily devotional time and prayer. Growing and learning is part of my journey as a hospice nurse.

ASPAC provides palliative care to patients who are terminally ill. Spiritual and emotional needs are also addressed and family is also included in the care.

I am rewarded in my work when my patients have a good day. A good day is defined as a day free of pain. I sometimes gently remind my patients to be grateful and to have a positive outlook.

My patients live in town, and also in rural areas so driving is part of my job. I often see the relief on the faces of family members when I arrive; because they are afraid. Their loved one is dying and they don't know what to do when a new problem occurs or when an old symptom re-appears.

I have been in awe of the bravery of the families that provide care for their loved ones. I visit and leave but they stay. There is a special love and I think that these

families have to be able to take care of a sick person every hour, day after day. I am humbled by their courage in the face of adversity.

As a nurse, I have seen pain relieved and agitation disappear when medications are titrated accurately. I know how important it is for me to assess and manage pressure wounds so they heal properly. It is also crucial for me to teach the carers so they know how to look after the patient well and keep him as comfortable as possible.

As a hospice nurse I deal with many symptoms; we do not know how each individual will react to the disease process but often there are predictable symptoms that occur. Compassion is key here. Working as a hospice nurse is rewarding but at the same time challenging. I like helping people to feel better; physically, emotionally and spiritually. Helping a patient live out their last days in peace, one day at a time is always my goal.

I have been blessed to be able to work as a hospice nurse, to serve the terminally ill patients who are making preparations to depart this world and enter the next. And I'm blessed to have the privilege of helping them. Thank you ASPAC.

by Satwin Kaur

*"It's a privilege to care for the sick.
It's an honour to be present when
humans are brought into this life and
when they leave."*

PET THERAPY WITH ARTHUR

Pet Therapy has been around for a long time, it is also known as Animal Assisted Therapy. When I worked in The Mary Potter Hospice in Adelaide I noticed patients became much more alert and responsive when their dogs visited them. They forgot their pain and the fact that they were in a hospice and that they had an incurable disease. Their faces lit up and were full of smiles when caressing and petting the dogs. Elderly patients with Dementia also responded positively to pets they could hold or stroke.

What is this special bond that humans have with canines? It could be that dogs are so non-judgemental of one's appearance; they give unconditional love and don't shy away from the smell of a fungating wound or a person who is disfigured because of a head and neck cancer. Dogs just live in the moment!

Recently, Arthur a friendly, loving Golden Retriever and his handler Mario, joined ASPAC as volunteers. Arthur has begun to make visits to suitable patients and although some are taken aback by his sheer size, they very quickly fall in love with him. He brings smiles and patients start to reminisce about their pets when they were young or tell stories and open up to the team in a way they have never done before.

by Dr Lalitha Jeyasingam



This 17 year old patient was happy to have Arthur visit. He talked animatedly about other friends with dogs and was busy taking pictures of Arthur.



Patient Mdm Palaniammal smiling as she strokes Arthur... Arthur seems pretty content too!

“ Petting, scratching and cuddling a dog could be as soothing to the mind and heart as deep meditation, and almost as good for the soul as prayer. ”

~ Dean Koontz (Author) ~

MAKING MEMORIES...

Creating memories before a beloved member of the family dies is important in the complex grief process humans pass through. It helps to nurture and strengthen the bonds between the dying child/adult with his family members and allows them to have a permanent reminder of a brief moment of joy ... of connectedness ... during a period of great sadness and despair. There are many methods and ways to do this such as photography, video making, simple craft work, moulds of foot prints and handprints etc.

At ASPAC we use water colours and engage the patients and their children, grandparents, cousins - to make colourful handprints on art paper. It is a messy but fun session which brings smiles and animated talk into an otherwise sombre room where a very ill patient is slowly deteriorating. It is important to seek permission before embarking on this as some parents or carers may feel it is against their culture or inappropriate. Staff and volunteers need to be sensitive to their emotions and respectful of their decisions.



Volunteer Maggie helping the young children of our patient paint their hands. The children get to choose the colours they want.



Nurse Satwin showing the patient the finished artwork which brings a smile to her face. Her daughter looks on.

*At the end of the day
all that matters is
LOVE and MEMORIES
so make sure you give it and
make sure you make them.*

~ Trent Shelton ~

VOLUNTEER TRAINING PROGRAMME I

A Volunteer Training Programme was conducted on February 27th for thirty participants. The role of ASPAC volunteers, Guidelines and Basic Introduction of hospice and palliative care was discussed following which Ms Malathy Cobey from the USA conducted a two-hour workshop on Touch Therapy with essential oils which saw enthusiastic participation from the crowd.



Thank you to Malathy for sharing her skills and knowledge!

L to R: Malathy Cobey, Dr L. Jeyasingam, Dr Teh Ee Von

COMMUNITY OUTREACH

The Baptist Church of Petaling Jaya, Selangor invited ASPAC to hold a 90-minute awareness session for the church members on 25th March 2018. A total of thirty people attended the talks which was conducted by Dr Lalitha Jeyasingam and Sister Mary Kristin FMM.



Dr Lalitha creating awareness about hospice care in the community.



Sister Kristin FMM (ASPAC Counsellor) discussing 'Grief and Loss'

VOLUNTEER TRAINING PROGRAMME II

A second Volunteer Training Programme was conducted on May 12th at ASPAC's premises in Petaling Jaya. Forty people attended and we were fortunate to have highly skilled facilitators like Dr Loh Ee Chin (Palliative Care Specialist, UMMC) who taught Communication skills and Ms Thang Mee Yuen (Clinical Psychologist) who conducted a two-hour workshop on Play Therapy to show participants how to use such a medium to facilitate the grieving process in patients and carers.



Participants and staff of the Volunteer Training Programme II



Dr Loh Ee Chin doing a role play with a participant during training.



Handling a bed bound patient.



Ms Thang (clinical psychologist) looking on as three male participants work creatively on their dough!

COMPASSIONATE PRESENCE - INTERFAITH APPROACHES TO PALLIATIVE CARE

A seminar was held in Petaling Jaya by WCCM (World Community for Christian Meditation) on June 9th where *Death and Dying* was discussed from the different faith perspectives by doctors, nurses, patients and family members. Dr Patricia Por who is ASPAC Chairperson and also the national coordinator for WCCM Malaysia gave the welcome address.

The speakers were palliative care doctors and allied health care workers from various hospitals and hospice programmes. The presentations were dynamic and informative. Dance, poetry and music was skilfully woven into the program adding depth and richness to the entire day.



Dr Richard Lim emphasizing a point...



*Odissi Dance "MOKSHA"
(the final liberation from birth and death is
the goal of life)*

Mr Sabapathy a cancer patient on follow-up with ASPAC shared his views on how a patient faces death and the choices he makes. Dr Lalitha Jeyasingam (Medical Director, ASPAC) and Sr Kristin (Grief Counsellor, ASPAC) were also speakers during the seminar. Associate Prof Dr Tan Seng Beng had the crowd in stitches with his humour while explaining the Buddhist perspective and Ms Tijah Chopil shared interesting information on the Orang Asli views on the sacredness of all different life forms and how closely connected we humans are to Mother Nature.

**Love and compassion are
necessities, not luxuries.
Without them humanity
cannot survive.**

~ Dalai Lama ~



MORPHINE MYTHS & FACTS

When we see our patients in palliative care, one of the many aims is to manage physical symptoms like pain and breathlessness. Often, when we first meet, they are in great discomfort, and sometimes morphine is recommended as the best choice in that given situation. However, we often find that the mere suggestion of starting someone on regular morphine is met with great resistance, despite it being a widely used medication with proven safety and effectiveness.

Here are some of the most common myths associated with morphine use:

"I don't want to be addicted to morphine."

When used appropriately for pain or symptom control, there is close to no risk of addiction. If for any reason the pain level improves, the medication can be tapered off safely. In this instance, it is important to follow the medical team's instructions to prevent withdrawal symptoms. However, often our patients stay on the morphine long-term because the disease process itself is irreversible.



"It's okay, I can take the pain."

There is no need to bear with the pain when there are so many different types of pain medication available. Long term pain will cause you to be tired, irritable, unable to interact with loved ones and ultimately lose enjoyment of your life.



"I want to save the morphine for when I'm really in pain, otherwise I will have no more options then."

Pain is easier to control if medication is started and adjusted early on, and lower doses are needed. When pain becomes severe and distressing, larger doses of medication are needed to bring it under control quickly. Morphine is also unique in that it has no ceiling dose, and the dosage can be carefully increased in consultation with your medical team until the pain is relieved.



MORPHINE MYTHS & FACTS (cont'd)

"Morphine will make my loved one die faster."

Palliative care does not aim to prolong or hasten death, and we are very confident of the fact that using morphine correctly does not cause an early death. The progression of illness will happen regardless of whether or not morphine is started, and our aim is just to support the patient throughout their journey.



"I will be too sleepy and confused if I take morphine regularly."

When the dose of the morphine is adjusted well, side effects such as these should be minimised. The aim is for good pain control AND good function.



"I don't want to take morphine, it will make me constipated."

It is true that constipation is a common side effect of morphine use, but this can be easily prevented if laxatives are started at the same time that morphine is prescribed, and used regularly.



"I vomited when I tried morphine last time, I must be allergic to it."

Nausea and vomiting are also common side effects of morphine, and does not indicate an allergy. Anti-vomiting medication can be prescribed together with the morphine to prevent this. In most people, this side effect is temporary and goes away after a few days.

by Dr Teh Ee Von

ANNOUNCEMENT

ASPAC Fundraising Dinner

We are appealing for the support of generous Malaysians, both individuals and corporations, to assist us to continue to look after all those who need our “hospice-at-home” care service. Every contribution received is appreciated as these funds will go a long way to cover operational expenses that allow us to continue to provide palliative care services *free of charge*.

Date:
11th August 2018
(Saturday)

Time:
7.00 pm

Venue:
Restaurant Super Tanker
(2nd Floor, Glo Damansara, 699 Jalan Damansara, 60000 Kuala Lumpur)

Kindly contact:
Julia (016 6283950) or Francesca (013 3950355) for further information or email **info@aspac.my**

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