

ASPAC newsletter

January-June 2019 Volume 8



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CONTENTS

Editorial	02
Certificate Course in Pallium India	03
ASEAPS 2019	04
Palliative Care Training Programmes	05-06
Volunteers' Activities	
· The Girl with 9 Super- powers	06-07
· My Volunteer Experience at ASPAC	08
· Music Heals...	08
· Musical Concert	09
Internship Experience	10
Common Myths About Palliative Care	11
Appreciation Lunch	12
Donation Form	12

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

‘Volunteer’ – A person who does some sort of service, especially helping other people willingly and without being forced or paid to do it.

Mother Teresa was one of the greatest volunteers this world has ever seen and she said... ***"I am a little pencil in the Hand of a writing God who is sending a love letter to the world..."***

We live in a fast-paced world where we are so immersed in our own hectic routines that we often have no time to stop to help someone who appears to be in distress or even ask ***"Are you ok?"*** No time to say ***"Hello"*** or to even smile at someone who crosses your path. Often, we don't know who our neighbours are... more so if one lives in a high-rise condominium. Most of us are guilty of living our lives in a self-centred way but there are still many people out there in the community who dedicate blocks of their precious time to serving others. These wonderful people have a name, 'VOLUNTEERS'!

Here at ASPAC, we are fortunate to have a committed band of volunteers who are loyal to our mission of providing compassionate, competent and loving care to all those who suffer from life-threatening illnesses. They go out on home visits where they meet the patients and carers. The time they spend chatting, laughing with them, giving hand and foot massages brings happiness. Sometimes they are required to just sit quietly and hold the hand of one who is too ill to talk but feels comforted by their compassionate

non-judgemental presence. We are fortunate to have a pet therapy dog Arthur and his master as ASPAC volunteers and they visit patients regularly. Arthur brings smiles wherever he goes!

Some volunteers help out at the reception desk answering numerous queries on the phone patiently. Others write out addresses, stamp envelopes for mail, key in data into the computer, type out lists of statistics, drive the nurses on home visits... the list goes on. Recently a small group of musically inclined volunteers have started to visit patients to entertain them; singing favourite songs with the accompaniment of guitarists. On-going fund raising activities are supported by volunteers.

We take this opportunity to thank all our big hearted volunteers. What would we do without you? No task is too small and each one of our volunteers serves with a smile, kindness and cheer. Thank you to all our dedicated ASPAC volunteers. You are **AWESOME!**

Dr Lalitha Jeyasingam

Editorial Team

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CERTIFICATE COURSE IN PALLIUM INDIA

By **SATWIN KAUR D/O HARBANS SINGH**



My attendance at Pallium India for the Certificate Course in Palliative Nursing from 3rd September - 13th October 2018 was an amazing experience. I learned a lot from various other members from all around India regarding their setup and management in palliative care. What I enjoyed most during my clinical posting was that I got to learn and understand the patient as a whole human being and not just as a "disease".

I also learnt how morphine trial is done on patients in severe pain before switching them to oral morphine to be taken regularly. In Pallium India, morphine trial (by IV injection) is done every 10 minutes till the pain score reduces or till patient falls asleep. I also learned lymphoedema

bandaging and the importance of lymphoedema massage before bandaging. I also learnt about other types of cheaper drugs that can be used for pain management.

The training included lectures, discussions, role-playing and 'hands-on' basic skills training, reflective learning, assignments, topic presentation, model exam, case study, clinical posting including inpatient posting, weekly exam and final exams, viva and practical test. In addition, practical skills training by facilitators was conducted, using a video link and training tools. All the materials for the training as well as the discussions and lectures were conducted in English.

Furthermore, I got to learn a lot about the patients at an in-depth level and understanding them better using the 4 aspects of holistic care, including the spiritual, psychosocial, emotional and physical.



Satwin receiving her certificate upon completion of the CCPN



Satwin with her fellow coursemates

Pallium India is a national registered charitable trust formed in 2003 aimed at providing quality palliative care and effective pain relief for patients in India. Pallium India works in collaboration with several national and international organisations to improve the accessibility and affordability of pain relief drugs, to ensure the availability of palliative care services in India and to improve the quality of palliative care services provided by the healthcare and allied health care professionals.

ASEAPS 2019

By DR TEH EE VON

From 11th to 14th of April 2019, two members of our ASPAC clinical team were given the opportunity to attend the 8th congress of the Association of South-East Asian Pain Societies (ASEAPS). This congress is held every two years, and this time it came to Kuching, Sarawak, with the theme '*Building Collaborations in Pain Management*'.

This year, there were over 450 delegates from 36 countries attending, with an impressive panel of international speakers from all backgrounds. There were pre-conference workshops on ultrasound-guided interventions for pain management, the transdisciplinary approach to care, as well as a general refresher for pain management.

Talks for the main conference covered various topics, including the global opioid distribution, cancer pain, neuropathic pain, pain sensitisation and much more. Presenters of note include Professor Fiona M. Blyth from Australia, who laid out the global burden of pain, showing the magnitude of the problem and demonstrating how morbidity from diseases may be a bigger problem than early mortality in the coming years. Associate Professor Stefan J. Friedrichsdorf from the USA spoke passionately on how pain in childhood affects pain perception all the way to adulthood, and advocates for an end to procedural pain.

President of the International Association for the Study of Pain (IASP), Professor Lars Arendt-Nielsen from Denmark, also contributed, explaining on pain sensitisation in chronic pain, stressing on the need to intervene and treat pain early. Prof Andrew S.C. Rice from the UK put to

rest speculation on the role of cannabinoids for neuropathic pain, making it very clear that there is no evidence to support the efficacy of cannabinoids in pain control, in fact laying out the possible adverse long term effects.

The prevalent message across the board is that there is so much more to do to improve pain management for our patients. More importantly for all of us clinicians, to remember that knowledge is shifting all the time and how we need to adapt our practice to new findings instead of just doing things the way we have always done.



Dr Lalitha and Dr Teh at ASEAPS 2019

It was also a good opportunity to meet with our colleagues from the department of anaesthesia and palliative care, and see what is going on in the region with the research papers discussed in the poster presentation. All in all, it was a useful experience, updating ourselves with the latest developments in the field.

"...morbidity from diseases may be a bigger problem than early mortality in the coming years."

Professor Fiona M. Blyth

PALLIATIVE CARE TRAINING PROGRAMMES

Jan-Jun 2019

30th January

Advance Care Planning Workshop

8th March

Introduction to Mindfulness in Palliative Care

23rd April

Volunteer Training Programme

15th June

Grief and Bereavement - Facing Losses in Children and Adults

Four training programmes and workshops were held in the first half of this year.

Barbara Edmonds, a participant in the Grief and Bereavement Workshop shares with us her experience and thoughts about the workshop.

The Grief & Bereavement Workshop held on Saturday, 15th June at ASPAC discussed adults and children facing losses. The attendees were drawn to this seminar either because they were health-care professionals in hospitals or hospices or had an interest in helping others who were grieving. It introduced the participants to an understanding of grief and its process, and explored spirituality at the end of life. Where I had thought 'grief' was experienced by one who was old enough to understand loss - an adolescent or an adult - grief was instead shown to be universal and experienced by all, even children and babies.

In the session on 'Overview of Grief and Loss', Dr Teh discussed the physical, emotional, mental and behavioural reactions of a person grieving and spoke about the stages of grief such as denial, anger, depression, bargaining and acceptance; from being loss-orientated to acceptance-orientated and all the oscillations in between the stages as we grieve (*Kubler-Ross model; Stroebe and Schut model*). Clearly it showed how each one's grief was very messy and unique, yet how important it was to grieve so as to finally accept the reality, to heal and move on with life.

We were also made aware of how important it is to take care of ourselves if we were the friend/carer; to be aware of our self and our own

feelings even as we cared for the grieving.

In the session on 'Grief in Children and Adolescents' Ms Thang, a clinical psychologist, gave us an understanding of the causes of children's grief from the child's understanding. We learnt of some "myths" adults hold on to when dealing with loss in children; such as, thinking adults must have all the answers and be able to teach children instantly about death or spirituality; or of avoiding these topics in the event of a death; or assuming the grief of an adult does not impact the child. Children grieve differently from adults. Their concept of death differs at different developmental levels, as well as the way they deal with grief.

It was very calming to listen to Sr Mary Kristin FMM, speak on 'Exploring Spirituality at the End of Life'. It placed grief in the context it is most often related to - the death of a loved one. She defined *Spirituality* as a recognition that we are all

**Grief can't be shared...
Everyone carries it alone.
His own burden in his own way.**

Anne Morrow Lindbergh

connected to one another in a power greater than all of us and our connection to this power and each other is grounded in *Love* and *Belonging*.

With this sense of togetherness, we can walk with the terminally ill in their world as they embark on their last journey. We are there to reassure, to listen and **be present**... and to be non-judgemental as they walk through their pain... till they can arrive at peace with self, with others, with God and Creation.

To put theory into practice, we worked in groups on case studies so we could identify the emotions of grief and suggest the action/help to be given as a friend.

The day ended with a meditative session of self-care which included aromatherapy, peaceful music in the background and 'Touch Therapy' where we did hand massages for ourselves and our friends. It was a day well spent...



Sr Kristin FMM, Grief Counsellor at ASPAC, speaking on 'Exploring Spirituality at the End of Life'



Gentle hand massages with creams blended with essential oils can bring a sense of relaxation and calm.

VOLUNTEERS' ACTIVITIES

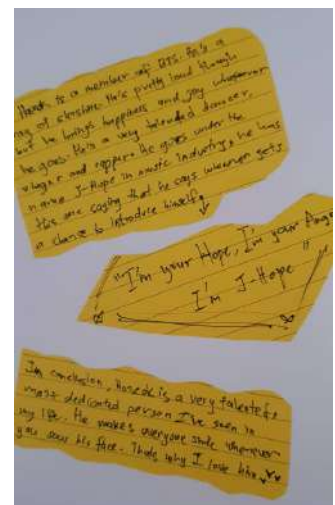
The Girl with 9 Superpowers

By ROHINI INDRAN

Art has always coloured my life. With that in mind, I joined Assisi Palliative Care (ASPAC), hoping to share the joys of art with others. After training as a volunteer, I was sent out with Nurse Roohini on my first visit. Anxious, as I did not know what to expect, Nurse Roohini introduced me to a very sweet and always smiling young lady, Navasakti.

Not knowing anything about her, the first thing that caught my eye when I saw her was her passion for music and her crazy fandom for the world of K-Pop! She had posters decorating her beautifully-painted blue room and mobile phone

and with her headphone by her bedside, I knew that she had a great ear for music. BTS is her ultimate idol, as she beautifully quoted them by journaling, "I'm The One You Should Love In This World explains the phrase of love and that it all starts with loving yourself first before giving your love to someone else".



J-Hope is her bias in BTS!

Navasakti is surrounded by love with a close-knit family always by her side. Her affection for her family is evident by her strong bond with her doting father and devoted mother. For good times and endless fun, she has three siblings who are her ultimate joys! Together they share about music, school and friends; and have created star-filled walls in her room, bringing the bright endless universe home for their sister.

I was told that Navasakti is an avid reader which was made clear to me when I saw her bookshelf lined with books of all sorts. She also shared that she was a writer with stories written online. Of course, being as curious as I am about her endless abilities, I immediately read through her stories and was amazed at her awesome flair for words! Thus, I introduced art journaling to Navasakti where she wrote and doodled a series of A-Zs of herself.

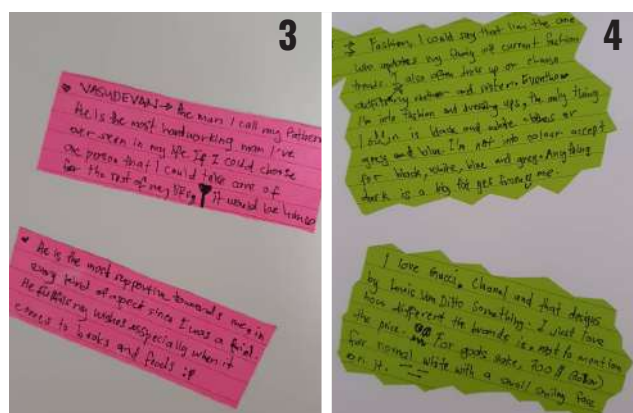
I learnt a little more about how interesting and intriguing Navasakti is with her journal entries from her interest in galaxies and planets to fashion, cooking, baking and such. This powerhouse will rock the world with her multi-talented capacity, I thought! So, I suggested to her that she work on her next artwork, a self-portrait of her "9 Superpowers", a literal translation of her name from Tamil to English.

I visit Navasakti every fortnight with art materials, books, magazines and anything I think she would love to indulge in. With her always perfectly manicured and beautifully painted nails, to her confident and infectious carefree spirit, Navasakti is an absolute joy to be with! I certainly hope that the little bit of art I share with Navasakti brightens her days as much as visiting her brightens my days! I have indeed learnt a lot about life and living from this smart young lady, especially to always put on a smile and to hold your head up high no matter what the circumstances are! *Rock on always dear Navasakti!*

Rohini is currently working for an international organization in the field of migration. She recently completed her Master's degree in Developmental Psychology, focusing on children with emotional and behaviour problems. She has been teaching art to children since 2008 as she enjoys sharing her love of art and helps children express themselves on paper with imagination and colours! Rohini's dream is to mix her passion and pleasure to help others feel happy and heal emotionally with art. She has been under the guidance of her mentor, master artist Jeganathan Ramachandram since 2005. <https://www.instagram.com/colourfulism/>

1. Navasakti showing one of her drawings.
2. Drawing her passion for music!
3. A journal entry dedicated to her father, Vasudevan.
4. Navasakti shares her thoughts on fashion in this entry.
5. Rohini with Navasakti.

Navasakti is a nineteen-year-old girl who has hereditary sensory motor polyneuropathy. It is a slowly progressive inherited disorder affecting motor and sensory peripheral nerves which causes weakness of her muscles. She is on an assisted breathing device, a feeding tube and needs full aid with all activities of daily living. She is still able to use her hands and the mobile phone is her window to the world and how she connects to her many friends, mainly on Whatsapp chat groups. If you were to describe Navasakti in one word, she is just...AWESOME!



My Volunteer Experience with ASPAC

By SHASMITA JAN SARKUNAN

I first heard about ASPAC through my uncle, who connected me with Dr Lalitha. I was looking for an old folks' home or hospice I could go to for an attachment with, as I wanted to learn how doctors practise medicine outside the hospital. As a medical school applicant, I wanted to broaden my view of the medical field, which I felt would give me an advantage during my medical school interviews. I never realised how big an impact ASPAC would make on my life, and this experience is something that I will cherish forever.

During that one week of attachment, I had the opportunity to shadow the doctors and nurses as they visited patients at their homes. I visited many patients from many different walks of life. Some of them were old, some of them were young. Some of them accepted that death was inevitable and were ready to go, some of them were angry and could not accept that their lives were slipping away from their fingers. My heart broke for these patients. They made me realise how fleeting life is, that our days are numbered. This was what pushed me to continue serving as a volunteer with ASPAC. Since life is short, we should use the time we have for good.

Staying on as a volunteer gave me the opportunity to attend workshops and teaching sessions organised by ASPAC for all its volunteers. I found these sessions to be very useful, as they touched on many important topics under the umbrella of palliative care. One session which interested me the most was the session on



Shasmita on reception desk duty...pictured with Kevin, a fresh volunteer.

anticipatory grief. It opened my eyes to the many emotions that are involved with losing a loved one, and taught me how important the grieving process is in allowing palliative care patients and their families to accept what is happening to them.

Before joining ASPAC, I thought that Medicine was the art of saving lives, and that the death of a patient meant that the doctor had failed to do his or her job well. Through this experience, I learnt that I was wrong. Doctors and other healthcare professionals are more than just healers; they are also counsellors, comforters, listeners, and so much more. I learnt that all these roles converge to one purpose, trying to provide people with a good quality of life, which is a noble cause.

I would like to thank Dr Lalitha, as well as all the other doctors, nurses, staff, and volunteers for giving me the opportunity to volunteer with you all. It has been an experience that has been invaluable and I will bring all the lessons I learnt into medical school with me. I would also like to thank all the patients I visited, who shared their stories with me and allowed me to be a part of their palliative care journey albeit for a fleeting moment. I will forever cherish our conversations and interactions.



Mdm Wee (ASPAC patient) with Nurse Satwin and Volunteers.

Music Heals...

Ruben Soosay is an enthusiastic and committed volunteer who goes the extra mile to make patients happy. He volunteers with ASPAC and has even got his friends to join him. Together, accompanied by a guitarist, they sing and entertain the patients in their homes livening up the atmosphere with their music. The patients have been so happy to have these lovely people spend thirty to forty minutes with them each time they visit.

Musical Presentation of the Apostles' Journey

By RUBEN SOOSAY

The Choir Ministry at the Catholic Church of Our Lady of Fatima (OLF) staged a musical concert on Jesus and His Apostles, covering the most crucial period on Jesus' life on earth, from His Last Supper to His Ascension into heaven and the descend of the Holy Spirit. The concert was held at the Temple of Fine Arts, Brickfields, Kuala Lumpur, on 30th June 2019 at 7.00 pm.

Not surprisingly, all the 600 tickets were sold out within a few weeks and the concert hall was fully packed. The distinguished guests who attended the concert included Archbishop Emeritus Murphy Pakiam, Fr Bernard Hyacinth, Fr Clarence Devadass and Board Members of the Assisi Palliative Care (ASPAC), which is a Not-for-Profit NGO providing free-of-charge Palliative Care Services which includes free medical care and support to terminally ill patients irrespective of race or religion, and much needed medical equipment like hospital beds, oxygen concentrators, wheel chairs, etc. which relieves the financial burden of the family of the patient as they do not have to procure such expensive equipment. All proceeds of the Musical Concert was given to ASPAC in recognition of the noble and much needed services provided by them.

The Musical Concert was very well received by all those attended and it proved to be a truly enjoyable night.

1. *The Choir Ministry presented a memorable performance.*
2. *The musicians.*
3. *Dr Teh Ee Von sharing with the audience the work done by ASPAC.*
4. *ASPAC staff and volunteers.*



INTERNSHIP REFLECTION

By **NG KUI FANG**

I was an intern at ASPAC for almost a month. During this period, I had the opportunity to observe the work the palliative care team carried out on a daily basis. It gave me a deeper understanding of what hospice care is.

ASPAC serves patients with terminal cancer by visiting them at their homes provided that they're located within 30 km from its centre. They provide palliative care for patients with advanced cancer and other progressive non-cancer illnesses like end-stage organ failure and advanced motor neuron disease. A team of trained staff provide expert medical care, while counselling is provided to the patients and their families on how to cope with their current situation. ASPAC has a cohesive team supported by an efficient management system.

Prior to this student attachment, I had a limited understanding of hospice care based on knowledge gleaned from books. I had only theoretical knowledge based on books read. I only heard from the shared experience of others and had no personal experience of it. This internship gave me a chance to have a better understanding of the profession of a medical social worker, which allowed me to further understand hospice care. It also gave me a new insight into what the meaning and value of life is.

Death is a terrible fact of life which can be overwhelming. When death is imminent, how can a patient face it with dignity? How does the family accede to a loved one dying without any regrets? ASPAC's medical team showed me how they alleviate the patient's sufferings, how to allay the patient's anxiety, and how to teach the patient's family to relieve the patient's pain by

using rescue doses of morphine or other medicines and also with non-drug methods like touch therapy etc.

Dr Lalitha, the medical director of ASPAC had tirelessly taught me a lot of medical knowledge and communication skills. Under her leadership, I learned how to develop a stable and professional relationship with patients and how to communicate effectively with patients.

As a student, it is not enough to master the basic professional syllabus and course material in Psychology. In practise, I have to gain more experience in order to improve my ability and skills, and I am able to understand the values in palliative care in a deeper manner. Internship in the palliative care centre had undoubtedly given me such an opportunity. It enabled me to recognize my own shortcomings in my practice and reflect on my own strengths and weaknesses.

I deeply admire the warm relationship between the medical staff, the patients and their family members. The patients and their family appreciate the services rendered to them with gratitude and thankfulness. The medical team likewise, are concerned about their patients' condition, pain control and their emotional condition, in the hope that they can live out the last of their days symptom-free and in comfort. Through this internship, I have benefited a lot. After listening to the clinical experience of the medical team at the daily morning meetings, I had an understanding of the psychosomatic status of the terminal cancer patients. In the process of contacting patients and their families, I developed a certain understanding of their problems and dilemmas. Through the process of communication with the medical team and patients, I realized my shortcomings. I would like to thank ASPAC for giving me a valuable learning opportunity. I had the opportunity to make a small contribution to the terminal cancer patients. Not only was I given the chance to contribute to society, it also gave me the opportunity to improve my professional practise and enrich my experience.

COMMON MYTHS

ABOUT PALLIATIVE CARE

Palliative care is often misunderstood and some people believe things about it that aren't true.

MYTH	FACT
<p>If I need palliative care it means I'm too ill to go home anymore.</p>	<p>You can receive palliative care in a range of settings including in your home, a hospital or a care home. ASPAC is a "hospice-at-home" care programme where the hospice staff will come to your home to see to your needs and help you in every way they possibly can.</p>
<p>If I have palliative care it means my doctors have given up and I'll no longer receive active treatment for my illness.</p>	<p>You can receive palliative care alongside treatments for your illness, such as chemotherapy and radiotherapy.</p>
<p>Having palliative care means I'm going to die soon.</p>	<p>You can receive palliative care at any point in your illness. Some people receive palliative care for years, while others will receive care in their last weeks or days.</p>
<p>If I have palliative care I'll no longer be seen by other specialists who know about my particular disease.</p>	<p>You can receive palliative care alongside care from the specialists who have been treating your particular illness.</p>
<p>Palliative care is just about treating pain and other physical symptoms.</p>	<p>Palliative care aims to provide a holistic approach to give you the best quality of life possible. This means caring for all your physical, emotional, spiritual, social and other needs.</p>
<p>Palliative care isn't for family and friends.</p>	<p>Palliative care teams are aware that your illness may have a big impact on your family members and friends. Palliative care teams do what they can to help people cope.</p>

If you have further questions about the information on this page and would like to find out more about palliative care, speak to your doctor, nurse or healthcare team looking after you.

THANK YOU FOR ALL THAT YOU DO

Staff and Volunteers were treated to lunch at the PJ Hilton by our generous benefactor



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**)

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