

ASPAC NEWS

VOL 1

July - December 2015

VISION

“DO EVERYTHING FOR LOVE EVEN THE MOST ORDINARY THINGS.”

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

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.

CORE VALUES

HONOUR AND RESPECT THE WISHES OF OUR PATIENTS

EXCELLENCE OF CARE

TO ALWAYS SERVE WITH COMPASSION AND LOVE

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FROM THE MEDICAL DIRECTOR

ASPAC (Assisi Palliative Care Berhad) offers you our first newsletter!

We would like to share our stories and activities with the communities we support hence the publication of this newsletter.

We have tried to give you a snapshot of events over the last six months - a season where many people from different places turned up out of the blue to help and support us. Bless you all!

The year 2015 went by at breakneck speed for those of us who work at ASPAC. It has been a challenging and exciting time, full of surprises and unexpected happenings. From moving premises, facing a shortage of staff, recruiting and training new volunteers, managing patients with difficult symptoms, networking with other organisations to provide more support to patients and families – it has been a busy time ... indeed, it has been a time of change and I suspect that things will continue to evolve at speed for some more time!

My grateful thanks to the ASPAC volunteers and our dedicated staff who have been such a staunch source of support. To the Board of Directors who are the invisible force that holds ASPAC secure – a big 'Thank You'.

I hope you enjoy our newsletter. Happy reading!



Dr Lalitha Jeyasingam
Medical Director

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FROM THE BOARD OF DIRECTORS

Assisi Palliative Care Bhd (AsPaC) - formerly known as Assunta Palliative Care Centre (AsPaCC) - was incorporated in July 2015 and is a company limited by guarantee and not having a share capital. We provide hospice-at-home palliative care services covering areas not served by other Hospices, where possible.

'Palliative Care' is a specialised way of providing supportive care for any person with a life threatening illness approaching the end of life. It is available for everyone: young and old, those with cancer or any other terminal diagnosis, people of any ethnic or cultural background, wherever they reside.

The idea of facing a critical illness such as cancer, end organ failure or other chronic life threatening illnesses is certainly daunting. At some stage in our lives we will encounter such situations whereby our loved ones, family, friends or maybe we ourselves are affected.

Statistics indicate that an estimated 90,000-100,000 people in Malaysia are living with cancer at any one time. It is estimated that one in four Malaysians (1:4) will develop cancer by the age of seventy-five years. The National Cancer Registry of Malaysia records 21,773 Malaysians being diagnosed with cancer but estimates that almost 10,000 cases are unregistered every year (NCR 2015). Many patients suffer needlessly from uncontrolled pain and other symptoms at home before they die.

Therefore palliative care services are very much needed and we hope to complement the services offered by the other Hospices in the Klang Valley.

We provide skilled, compassionate palliative care to ameliorate symptoms and relieve suffering, thereby improving quality of life for patients and families. The home care team consists of a doctor, nurses, counsellors, medical social worker and volunteers. We also provide medication, medical equipment and bereavement support.

All these services are free of charge to the patient and funded by generous donations from Corporations and individuals. We aim to 'Do everything for love, even the most ordinary things' and in the words of Dame Cecily Mary Saunders (founder of the modern palliative care movement) – "You matter because you are You. You matter to the last moment of your life and we will do all we can, not only to help you die peacefully but also to live until you die".



Dr Patricia Por
Chairperson, Board of Directors

A CARER'S STORY

BY MRS ANNA HUE

MRS ANNA HUE DESCRIBES HOW IN THE LAST FEW WEEKS OF CARING FOR HER BELOVED TERMINALLY ILL MOTHER-IN-LAW, MADAM LAM YOON THYE, ASPAC HOME CARE PROGRAMME HAD HELPED HER AND HER FAMILY COPE WITH THE CRISIS.



The late Madam Lam enjoying a home-cooked meal...

My mother-in-law was diagnosed with Stage 4 lung cancer. The news was a blow to the family. Aged 89, she had generally been in good health and had regular medical check-ups every 6 months.

From the time I got married to my husband 39 years ago, my mother-in-law had stayed with us. She had been more like a mother than a mother-in-law to me. I had lost my own mother when I was a teenager. So, I was fortunate to find a mother figure in this remarkable woman.

My mother-in-law had been having bad coughing spells and shortness of breath in April but she refused to be taken to a clinic or hospital.

On the night of May 4, 2015, she had difficulty in breathing. Despite her resistance, we took her to hospital nearby. Emergency treatment was given before she was transferred by ambulance to the General Hospital KL.

After a battery of tests, scans and examinations, we were told the grim news – her condition was bad, with fluid building up in her lungs.

In the weeks that followed, the doctors did two pleural taps to drain the fluid from her lungs. The specialist had suggested treatment by pleurodesis, a procedure which might prevent or delay fluid forming in her lungs again.

However, we were not totally comfortable with this as the procedure would still not be able to treat the cancer. We were told that hopefully, it might help her to breathe better. The doctors also said that at her age, surgery to remove the tumor in the lung or radiotherapy was not recommended. So we asked, "What's next?" We had accepted the fact that her condition was terminal. One specialist said that she might survive another three to six months.

Finally, we opted for palliative care. She had been in and out of hospitals for three weeks and she wanted to be taken home.

My mother-in-law was referred to ASPAC Home Care Programme. They loaned us equipment like an oxygen concentrator, ripple mattress etc. In a matter of days, we equipped her room with all the necessities. We had to buy, borrow or rent. We had a wheel-chair, a walking frame, a hospital bed, bubble mattress, oxygen tank, oxygen concentrator machine, sterile hand gloves, antiseptic wipes, etc. One day, I almost had a breakdown when I found that one of us had forgotten to turn off the nozzle of the oxygen outflow and the oxygen tank was empty!



The late Madam Lam with her grand-daughter and family dog

Being at home had some advantages. My mother-in-law was in her own room, which made her feel more secure. We could cook her favorite dishes in an attempt to boost her failing appetite. We contacted her siblings, nephews and nieces and

some came from afar to visit her. All her children and 7 grand-children and great-grandchild had the opportunity to spend some quality time with her too. The family pet poodle "Cookie" acted like her guard-dog, checking out all visitors before allowing them access into her room.

In the five weeks until she passed away, it gave all those who mattered to her, enough time to say their goodbyes. In the last few days, my mother-in-law could not swallow and became increasingly breathless. She was started on continuous infusion of medicines in a syringe pump. None of us have been trained as nurses or doctors and we had to learn fast on how to deliver professional care.

We were very grateful to Dr Lalitha Jayasingam and nurse Emelda from ASPAC. They patiently taught us how to administer morphine, insert enemas, set up the drip, etc. They visited us everyday during the final two weeks and gave us strong moral and emotional support.

On 11 June 2015, my mother-in-law passed on peacefully without struggle. While we grieve, we also want to rejoice that she had a rich and beautiful life on this earth.

MY STORY

BY MADAM FONG WAI HENG



... Dawn breaks for another new day ...

- FONG WAI HENG -

My name is Fong Wai Heng .I am 62 years old . I was diagnosed with Breast cancer in 2010. I underwent surgery followed by chemotherapy and radiotherapy.I was well for some time . Unfortunately in 2013 the cancer came back and spread to my liver.Today I am still under treatment and follow up at the hospital.

During the difficult times I was going through ,my oncologist referred me to AsPaC .I really appreciate the nurses and doctor for their visits to my home to see me. Their loving care has helped me overcome my pain and discomfort . They make me feel like going on even during dark times .

Mdm Fong passed away shortly after sending us this article . We regret that she did not get to see her words in print . We salute her free spirit , her courage and her positive approach to Life .

DATIN SIVAMANI RASIAH GIVES AN ACCOUNT OF HOW SHE WAS DRAWN INTO VOLUNTEERING AT THE ASPAC HOSPICE HOME CARE PROGRAMME. SHE DESCRIBES THE TRAINING SHE HAD TO UNDERGO...

In June this year, when my friend Kamala asked if I would like to be a volunteer at the ASPAC Hospice Home Care Programme, I immediately turned it down because I felt that it would be depressing and painful. But after hearing stories about the happiness, care and comfort that volunteers could bring to these terminally ill patients, I thought, "Why not give it a try?"

The first training session was held on Saturday, 11th July 2015 at the ASPAC Centre at 32 Jalan 1/12, 46000 Petaling Jaya Selangor Darul Ehsan.

We were warmly welcomed by Dr Lalitha Jeyasingam, the Medical Director, who introduced us to the other staff. We soon got to know the other volunteers as well. Although most of the volunteers were senior citizens, I was happy to meet some young university students as well.

Dr Lalitha started off the training with an introduction to Hospice and Palliative care. I was fascinated to discover that the word "hospice" is derived from the Latin "hospitium" which means 'hospitality' and that during the Middle Ages, the nuns and monks had also offered shelter, food and care to travellers who unfortunately contracted illnesses along the way and had died in these convents and monasteries thus giving rise to a very early form of 'hospice'. Dr Lalitha also shared her experiences working in several hospices, both in Malaysia and overseas.

Sister Mary Kristin FMM, Grief Counsellor, counselled us on how to handle grief and loss as volunteers. She suggested very practical steps to handle stress through gardening, walking and exercise, listening to music, sharing with friends, meditation, keeping a journal and simply being grateful and counting our blessings.

A slot I found very useful was "Boundaries and Self-care" by Sharon Dabi, the Nurse Manager. She spoke of the need for strong boundaries between work and life and the need for balance.

Sharon warned of the dangers of burnout, physically, emotionally and spiritually and the need for us to acknowledge our own vulnerability as volunteers. We must be aware of the need to process our feelings of grief and pain when we empathise with our patients and when we lose them.

Sharon shared a Self-Care plan where we can take care of our physical body by listening to our body and taking care of it, by exercising, massages, yoga, breathing exercises and conscious eating. Emotional and cognitive self-care is necessary to soothe, express and release mental anxiety. Some ways are quiet contemplation, meditation, healing music and the best, laughter! In addition, spiritual self-care can be through prayer and meditation. Even the listing of the positive things in our lives and doing random acts of kindness can be empowering.

There was a session on the role of volunteers in the Hospice Programme. Through the many anecdotes and stories shared, we learnt of our roles, the boundaries that we should not breach and the self-care we must exercise so as not to be taken advantage of!

ASPAC also held a second training session for the volunteers on Saturday, 5th September 2015. Dr Lalitha spoke on "End of Life Care - The Terminal Phase" while Sharon spoke on "Infection Control".

While these sessions added to our knowledge and were valuable to equip the volunteers for these situations, I felt a bit overwhelmed and pray that I will not have to handle these cases for now.

During these training sessions, we could feel the dedication, care, love and joy of the staff for their vocation. We felt empowered by their sheer determination to help their patients.

I hope that I will be a good volunteer, helping in some small way, to bring comfort and ease to those who are in need.



Battle of words... Datin Sivamani and Kamala play Scrabble with a patient

A STUDENT OF PSYCHOLOGY SPENT A SHORT PERIOD AT ASPAC; SHE SHARES WHAT IT IS LIKE BEING A VOLUNTEER AT ASPAC...

My time volunteering with ASPAC was for a period of approximately two months - beginning mid-June 2015. Currently studying for my undergraduate degree in Psychology, I have a keen interest in the topic of bereavement and grief and ASPAC offering palliative care seemed a suitable meeting point for my interests.

After a brief meeting with Medical Director – Dr Lalitha, I was placed under the guidance of the team's grief counsellor, Sister Mary Kristin. My brief stint at ASPAC began on a practical note - I accompanied Dr Lalitha and Sister Emelda to visit an elderly terminally ill patient in his home.

The visit involved interacting with family members of the patient. Meeting them under sad conditions where emotions are fragile did initially intimidate me. However, the family welcomed us into their home warmly and this allowed for more productive home visits.

On most visits to patients' homes, I took on the role as an active listener and observer. The ASPAC team was most gracious and patient in listening and answering any questions I might have – and especially so in explaining medical terms.

Normally, I would visit four patients daily in various home locations in the Klang Valley; I often came home tired – physically drained but even more so mentally exhausted after observing and listening to patients, caregivers and family members.

After a couple of weeks, the cases began to blur into one another. Every other case seemed to hold the word 'cancer'.

Many of the patients were in their 70s. Each had a story that unfolded as I talked to them. They were more than just a 'case'. They shared their stories of who they were before they fell ill. It included their achievements, their personal struggles and experiences.

Their stories inspired me. Often, at the end of each day, I would take a moment to reflect on the day's events. I am grateful for the insight that volunteering with ASPAC has given me.



Listening to patients is part of a day's work. Pik Wah (right) with Dr Lalitha

A FUN OUTING

BY SHARON DABI

A FUN OUTING FOR A SPECIAL FAMILY WAS ARRANGED RECENTLY BY ASPAC HOME CARE PROGRAM TEAM

Two of our young patients – Mohamad Amirul Akmal age 11 years ;and his brother six year old Mohammad Ammar Amsyar- were taken on a fun outing with their family to KLCC on September 6th 2015. Both suffer from a genetic disorder, Duchenne Muscular Dystrophy. It was the first time in two years the boys had been out on a day trip with their mother and two sisters .

The trip entailed much planning as the physical needs of the boys had to be seen to at all times . The trip included a visit to the Aquaria, lunch at KFC and shopping at Cold Storage supermarket.

Although it was tiring , it gave a sense of fulfillment to all involved in the outing to see the joy on the faces of the boys and their family members .

The trip was sponsored by the BEC members of St Francis of Assisi Church in Cheras . Appreciation also goes to Pauline Kuan, Julianna Loh Kooi Sim , Melvyn Kuan , Judy Song , James, Teresa , Zanariah and Siti.



left to right :Intan (our medical social worker),siblings and mother of the two boy patients; Extreme right is Sharon (our nurse manager) carrying the younger patient Mohd Ammar Amsyar. Boy in wheel chair is Mohd Amirul Akmal.



Some of the Members of the BEC who helped organize and fund the outing ; together with AspAc staff and patient and family members.

WISE QUOTES..

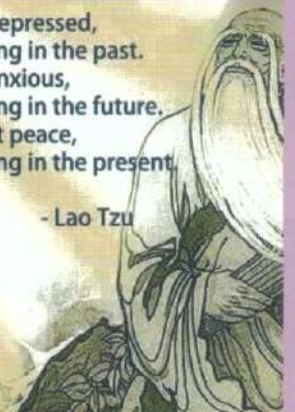


"Clouds come floating into my life, no longer to carry rain or usher storm, but to add color to my sunset sky."

Rabindranath Tagore

If you are depressed,
you are living in the past.
If you are anxious,
you are living in the future.
If you are at peace,
you are living in the present.

- Lao Tzu



MY JOURNEY AS A PALLIATIVE CARE NURSE

BY SISTER EMELDA YAN

“I CAN DO THINGS YOU CAN’T, YOU CAN DO THINGS I CAN’T: TOGETHER WE CAN DO GREAT THINGS.”

- MOTHER TERESA -

Two years ago, a decision was made by my congregation (Sisters Of St Francis of Sarawak) to send me to Assisi Palliative Care (AsPaC) in Petaling Jaya , Selangor to learn and gain experience in palliative care. I left The Home of Santa Clara in Kuching Sarawak on 10th June 2013 to work in AsPaC.

It was very challenging and tough for me in the beginning because everything was new to me. I knew nothing about palliative care... I had never heard about it before! I also found to my dismay that I had to drive to many areas in the Klang Valley and use a GPS which I was unfamiliar with. There were many obstacles (my English was poor, I usually conversed in Bahasa Malaysia in Sarawak) and trying circumstances. Some days I would end up in tears, convinced I could never be a good palliative care nurse.

In AsPaC, I attended courses about palliative care and I learned ‘on the job’ from the other nurses in my team. They often helped me and taught me what I needed to know. I also learned from the patients whom I cared for. They helped me understand and appreciate life better. As I journeyed with them during the last stages of their lives, I learnt about courage, hope, endurance and faith.

Sometimes I felt frustrated and helpless when unable to manage symptoms especially when the patient was in pain. However, most of the time we **CAN** relieve pain and other symptoms .It gives me great satisfaction when I see my patients free of symptoms and able to have some quality of life despite the advanced state of an illness.

Two years have flown by quickly! I look back and see that all the challenges I had faced have helped to build my confidence and given me a much better understanding of people and palliative care. Now I can proudly say that I can manage pain and other symptoms well and I am also skilled at carrying out nursing procedures.

I find that palliative care really does improve quality of life for the patients and their family. I believe that my presence, love, care and concern for the patients and families brings comfort, hope and a feeling of security .I feel fulfilled and happy when I can achieve the goals of care for my patients.

I am grateful and thankful to my palliative care team who helped and supported me along the way. Without their love, support, and care I would not have been able to make it on my own and I might not be the person who I am today.

I really love doing this job. So, when my Superior General Sister Flora asked me to return to Sarawak, I had mixed feelings –happy to go back but sad to leave behind my patients.

I leave AsPaC at the end of this year to serve our own Nursing Home in Kuching . With all the experiences and the knowledge I have obtained at AsPaC, I aim to give my best in Sarawak. It is also my dream to open a day care center or an In- patient Hospice facility to serve patients in Kuching in the future.



Sr.Emelda Yan at bedside of patient. His wife and grandchildren are in the background

A SPECIAL EVENT..

...In Memory of Loved Ones Who Have Passed On...

A Memorial Event was held on 10th October 2015 to honour the memory of the patients we had looked after under the AsPaC home care program. About fifty family members, friends, volunteers and staff turned up for the ceremony. Families brought pictures of their loved ones which were displayed on stage. Candles were lit and a minute of silence was observed as a mark of respect for those who have passed on. Prayers from different religions were said, followed by flower tributes and writing of messages. Soft music played in the background by wonderful couple Ivan and Marie added a deeply reflective mood. Sisiter Mary Anne read a poem which moved several people to tears.

There was sharing of memories by some carers whilst many other family members went on to chat with the ASPAC staff, to reminisce about their loved ones.

The ceremony ended with a luncheon.

Many thanks to all staff and volunteers who worked hard to ensure the success of this event.

“It is only for a time that we must part. So bless the memories within your heart.”



Dr Ted Hoo (AsPaC Board of Directors) lights the first candle to start the Memorial ceremony watched on by Dr Lalitha Jeyasingam



AsPac staff and volunteers who contributed towards the success of the event.



A poignant mood among the audience as guests reflect on memories of their cherished ones who have passed on.



Sharing memories of loved ones who have passed on brought tears for some.

TO THOSE I LOVE AND THOSE WHO LOVE ME

When I am gone , let me go –
I have so many things to see and do .
You musn't tie yourself to me in tears ,
Be thankful for our many beautiful years .

I gave you my love, you can only guess-
how much you gave me in happiness.

I thank you for the love you each have shown-
But now it is time I travelled alone .
So grieve a while for me , if you must .

Then let your grief be comforted by trust –
It is only for a time , that we must part.
So bless the memories within your heart.

I won't be far away, for life goes on-
So if you need me , call and I will come .

Though you can't see or touch me, I'll be near-
And if you listen with your heart-
You'll hear all my love around you, soft and clear.

And then, when you must come this way alone ,
I'll greet you with a smile and say,
“Welcome home ”.

By Lois Cartnell

WHEN YOU NEED A COMFORTING TOUCH..



Animal assisted therapy forms a part of our care. A gentle, friendly pet fulfills the basic human need to touch and helps patients deal with anxiety and stress during their illness. Socially interactive dogs are screened and 'interviewed' to provide comfort to those who need it - especially those living in isolated conditions.

WISE QUOTES..

May God from whom all living beings come, and to whom all will return, grant us the gift of wisdom. He is fire and the sun; He is the moon and the stars; He is the air and the sea; He is this boy and that girl; He is this man and that woman; and He is these old people, leaning on their sticks. He appears in countless different forms.

He is the bird with blue feathers, and the bird with green feathers. He is the cloud from which thunder rolls and lightning flashes. He is the seasons of the year, and the waters that cover the oceans. He has no beginning, and He has no end. He is the source of all things.

From God all types of living beings acquire their names and forms. He determines what will give them pleasure, and what will cause them pain. Each type of living being is distinct and different. But when we pierce the veil of difference, we see the unity of all beings.

~ Svetasvatara Upanishad: 4.1-5 (The Veil of Difference)

~
'Just as treasures are uncovered from the earth
So virtue appears from a pure and peaceful mind
To walk safely through the maze of human life
One needs the light of wisdom and the guidance of virtue'

~ Buddha ~

Learn to love without condition
Talk without bad intention
Give without any reason
And most of all
Care for people without any expectation

~ unknown ~



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: _____

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Please accept my contribution of : RM _____

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Please make cheque payable to **ASSISI PALLIATIVE CARE BHD**
Cheque to be posted to **32, Jalan 1/12, 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.