

ASPAC newsletter

July-December 2020 Volume 11



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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

The pandemic continues to rage across the world with new, more infectious strains. We in Malaysia have not been spared, entering a third wave of infection with continual rise in numbers to four digits in the last quarter of the year. Thus, the RMCO was reverted to CMCO and, if the numbers did not subside, impose a threat of MCO 2.0 (*at the time of writing*).

The public health system was fully stretched and we were advised to keep our Palliative Care patients comfortable at home and out of hospitals as far as possible. This posed a further challenge to us as our medical and nursing staff were already working under huge constraints in not being able to give the best of care to our patients. We had to make do with increasing the video calls, however, nothing can replace a touch, a hug of comfort and sitting down side-by-side with the patient or caregiver; providing a listening ear. When a visit was necessary, the staff were hampered from providing ideal care when they appear in full PPE (Personal Protective Equipment), looking like creatures from outer space!

Funding remains a big challenge as our biennial Fund Raising dinner scheduled in August 2020 had to be cancelled. Thankfully, with your generous support, we had a successful

Christmas cake sale and going forward, will continue to raise funds in other ways. Even though the cost per patient visit has gone up, we do hope our benefactors will support us in contributing towards sponsoring a patient's care on a monthly basis as outlined in our new donation form at the back of this publication. It would be most helpful if we could receive a steady flow of income to assist in covering operating costs.

In order to expand our services, we also need more medical and nursing staff. While sourcing for suitable staff remains another challenge, this can only be realised with adequate funding. Thus, any donation however small will be much appreciated.

We look forward to your continued support.

Our best wishes for a better 2021!

Thank you.

Dr Patricia Por
Chairperson, Board of Directors

The most beautiful things in the world cannot be seen or even touched.
They must be felt with the heart.
Alone we can do so little; together we can do so much.

~Helen Keller ~

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MAINTAINING SERVICES IN THE COVID-19 ERA

By DR TEH EE VON

As the world progressed through the COVID-19 pandemic in the past year, it became clearer with each passing day that there was not going to be a 'back to business as usual' scenario anytime soon. Everyone had to settle on what they would be able to accept as a 'new normal'. Here in ASPAC, the chaos and high emotions of the initial waves were quickly put in check because we still had to continue helping our patients live as best they can at home, regardless of what viral war is raging outside their doors.

Community palliative care is all the more important at the moment because many patients are reluctant to go to the hospital. Some have fears of being exposed to the virus with the crowds, but some also have the very real fear of being hospitalised alone with no family members allowed in. The hospitals also depend on us to hold the fort, because we are the first line of medical care that the patients can access. If their problems can be addressed at home, admissions can be reduced – giving our stressed and overworked hospital colleagues more space to breathe.

One of the biggest challenges with the COVID-19 virus is that an infected person can be without any



Preparing injectables from car booth in front of patient's home.



symptoms in the beginning and some remain asymptomatic throughout the illness. This allows them to continue with their daily activities therefore unknowingly spreading it to others. This is the basis for advising everyone to wear masks and socially distance. Not just to protect the person with the mask, but to stop them from being an unwitting source of viral spread.



Assessing patient at home.

This is why the ASPAC team still wear a significant amount of PPE (personal protective equipment) for each of our home visits. This not only minimises the risk of any of our staff being exposed, but more importantly, prevents us from unknowingly carrying it along to other patients. This practice is costly, and uncomfortable for the staff, but our patients have enough problems of their own without us bringing more stress to them.

The show must go on.

We must all play our part in the new normal.

Are you?

Wear a mask. Wash your hands. Socially distance.

CARING FOR MY AUNT RENEE TALALLA

By **SANDRA SOLIANO**

I struggled in writing this piece, because losing Renee sent a ripple of shock waves through the family. And though it's now been 18 weeks since the day (September 13th 2020 at 3.03 pm Sunday) the ache is still there.....

My aunt, Renee Talalla, was a remarkable soul. Intelligent, well-read, articulate, funny and loving with a heart that gave and gave.

On June 5th 2020, with the prognosis of the final CT scan, Renee came under Assisi Palliative Care. This was also the day I came into the picture. There was never a question in my mind that I would not be there for her. Renee was fortunate that she had a strong supportive team in her corner. There was my Uncle Bert, Mohammad (a 'foster' son) and Jane, a Filipina helper, at the core, and an army of friends and family circling attentively close by.



I chose to do the overnight shift. I saw this as the time when the household was silent and dark and the time Renee would feel the most vulnerable, lonely and scared.

As time went on, we established a night routine. I would sit as close as I could get and hold and stroke her gently till she slept off. At times, she would have me lying in her bed to cuddle. It was all about the reassurances, of feeling safe, of knowing that she was not alone.

Renee was meticulous, always jotting down in notebooks, anecdotes, reminders etc. Here too, she began jotting the medications she was taking, her levels of pain and snippets of what was happening to her body. We, the care givers, took over this recording, duly noting the time we administered the various medications - there were many, pain levels, sleep and bowel habits, etc. And

even then, with all this precise recording we had two horrendous oversights and failed her. Once we forgot the 9 pm Lyrica and on another occasion to change the Fentanyl patch. Both times we caused her pain level to spike. The guilt Mohammad and I felt was enormous.

It was not all gloom and doom. There were lots of happy times, laughter and bantering, fun visitors with songs and dance, creative meals, walks in the garden and bizarrely, even the selecting of the outfit (that Renee wanted to be buried in) was a hoot that had Renee in stitches.

In June, Renee was mobile, vibrant, slept well and enjoyed her meals. Her pain level at 4/10.

In July, Renee was still mobile but unsteady. Her sleep patterns changed at night; waking up frequently. Felt pain in her

jawline and headaches. Was disinterested in food. Pain level increased to 8/10.

In August, Renee would nod off in mid-conversation, initially for a few seconds that then stretched into minutes. She needed more support to walk and limited herself to just her room and the family room. Enjoyed having visitors and her face would light up in recognition. Dreams began to set in and she did not like sleeping in a dark room.

By September, Renee was too weak to walk so days were spent in her chair or in bed. Recognisable changes in breathing, reduced intake in nourishment, reluctance in taking meds, erratic sleep, eyes looked vacant and at times, Renee may say something or make a gesture that seemed out of place but actually wasn't. I will come back to this line later.

Being a care giver to someone under palliative care, knowing where this journey will lead, understanding that the journey will go through turbulent times, realising fully when the journey ends it ENDS. Full-stop. That you may be there at that precise moment. Add to this jumble of feelings - that you are a close-knit family and this is someone you dearly love - you take all this into account. You do your best, your very best. Little innovations or adjustments to give that extra bit of comfort and reassurance ... a diffuser that emits essential oils and has a soft glow ... background music ... write down the meds in plain view ... mash up pills and mix with a bit of honey for easier swallowing ... ensure a bright and airy room ... keep everything neat and in easy reach ... keep siblings and family connected with calls and photos...

This was something I wrote for a new care giver in mid-August so she could understand my aunt better.

"Don't rush Renee. Renee needs time to adjust, think and assimilate.

Don't force Renee. Renee has a mind of her own, forcing her, even if it's for her own good, makes her rebel.

Don't crowd Renee or come into her face. Give her space."

The day I dreaded finally dawned. It was Sunday, 13th September. There were visitors earlier in the day. Renee recognised every face and smiled. In the last few days, Renee developed thick globs of phlegm that had to be scooped out by finger. The phlegm made speaking difficult, made swallowing difficult, made breathing noisy. As soon as I got back from buying provisions at about 2.30 pm, my uncle with the new Filipina care giver left for the pharmacy to buy something to help scoop out the phlegm. I was sitting next to her bed and simply talking to my aunt. Renee was propped up in bed and staring and then she raised her arms as if to hug. I jumped up and responded with a hug. When I looked at her face, there was a bit of spit drooling so I took a tissue to wipe. But more spit came out. And I made a joke about this. Then she gave a shudder. It took me another second or two to realise that she was 'all quiet'. She was gone. She left peacefully.

Later I was told that that shudder she made was actually her last breath. Staring past me and raising her arms was to someone she 'saw' in the room. The same too when she sometimes said or made a gesture that seemed out of context... it was figures that she saw in the room. Sometimes too it seemed that Renee was reluctant to leave. People say because some business is unfinished. Working on this possibility, my cousin and I contacted two such 'lost relationships' we felt Renee needed to hear from. I played the WhatsApp video from this second person early Saturday morning. I said who it was from and I saw the amazement written across her face.

I cannot express enough the part the Assisi Palliative Care team played in all our lives. The care, comfort and support of Drs Lalitha and Teh, nurses Satwin and Roohini and Sr Kristin is unsurpassed. There were many nights that I called in panic, needing guidance or to reconfirm my actions. Every time the voice on the other end was calm and soothing. They guided us and gave us the confidence.

Their efforts and the work they perform so tirelessly are invaluable. For someone like me who had no idea what to expect, they guided me and helped me care for my aunt the best I could and for that I will always be extremely grateful.



My Aunt Renee with Uncle Bert; whom she affectionately calls, Bertie.

BEING A CAREGIVER TO MY BELOVED GODMOTHER

By **MOHAMMED**
(A Yemeni Refugee)

Being a caregiver to Renee Talalla who was my Godmother and my best friend, and the most valuable gift I got from the Lord, was the hardest thing I've ever done.

I was happy that I was allowed to be there for her, to be there for the person who had been there for me and my family the most.

But, it was hard to see her in pain and uncomfortable. I had no experience or knowledge about how to take care of someone who has been diagnosed with the terrible disease, *Cancer*... I was so nervous - afraid to make her feel uncomfortable or to cry in front of her - so that she doesn't get sad. The only time I could release my tears, to bring out the sadness of what my beloved mother is going through, was at night when I was alone. It was hard because of what my Godmother meant to me. It was hard because of how intelligent she was, I did not want to make her feel like a cancer patient. The last thing I wanted was to make her feel uncomfortable.

So, I read a lot about how to treat cancer patients on the internet and what to say and what not to say. But my Godfather told me, "You might find some good points but the internet doesn't tell you who the patient is," which is very true and made it even more difficult for me.

However, with the help of ASPAC, I was able to learn how to make her feel comfortable through



Mohammed with his Godmother, Renee.

small things. That made a big difference. I've learned a few points that I will carry throughout my life which will help me when the time comes to take care of my own parents.

The most important part that I've learned is that the carer has to be very careful about how to make the patient feel about their pride. Never make them feel that they are doing or saying things wrong. Be patient and caring.

I've learned a lot that I will keep inside me forever. Thanks to Dr Teh, the ASPAC team, my Godfather Albert Talalla and Aunty Sandra.

May God bless you for the care and the comfort you gave my mother.

God bless.

*Goodbyes are only for those who love with their eyes.
Because for those who love with heart and soul,
there is no such thing as separation.*

- Rumi -

VISIT BY THE U.S. AMBASSADOR



We were honored by a visit from the U.S. Ambassador, Kamala Shirin Lakhdhir who wanted to meet our Palliative Care Team who attended to her late friend, Datin Renee Talalla.

She made a personal donation in loving memory of her dear friend and thanked the Team for their care.

On hand to greet the Ambassador were Board Members Dr Ted Hoo, Dr Patricia Por, Dr Asma Omar and our Medical Director, Dr Lalitha Jeyasingam.

ATTACHMENT STUDENTS FROM UTAR

By DR TEH EE VON

Some 4th year medical students from UTAR (University Tunku Abdul Rahman) came to ASPAC on 30th September 2020 for a half-day attachment to gain exposure in regard to community palliative care. The nine students were on their Family Medicine posting, which included an introduction to palliative care.

Our palliative care nurses Roohini, Satwin and Aneesha started off by teaching them practical things that caregivers need to do when caring for seriously ill patients, e.g. oral care, prevention of pressure injury and handling techniques. Often this is forgotten when talking to patients and family members about their illnesses, and they are at a loss when discharged home.

Dr Lalitha then spoke about the transition of care from hospital to home setting and the common issues that arise when there is lack of proper referrals and communication between the hospital and community team. Our grief counsellor, Sr Mary Kristin talked about the psycho-socio-spiritual issues that the patients and their families go through at the end of life, and how best for the medical team to handle it.

The students felt it was an eye-opening experience, as they were impressed with the whole-person approach to the patient in palliative care. They were also grateful to have been introduced to issues like grief and bereavement, as well as the importance of communication skills when handling serious illnesses. We hope that they have learned from this, and will carry on to be advocates of palliative care as they embark on their future career.



The following were amongst the feedback we received:

"..communication skills are important in breaking bad news and managing patients."

"..importance of ethics and holistic care ... to treat them as human beings."

"..left a deep impression on me, I will remember it for life and apply it in my career."

CHRISTMAS FUNDRAISING

By **ANDREA PAVEE**
(ASPAC Volunteer)

Last Christmas, to kickstart our fundraising efforts, we mooted the idea of selling Christmas cakes.

It had not been done before but with social distancing a norm, having the usual Fundraising Dinner was not possible, or feasible.

The idea caught on - and it was all hands on deck to make the idea a reality.

Sourcing the Cakes

Mrs Wong Sook Harn, a member of the Board of Directors proved invaluable in sourcing and selecting a variety of cakes for our initial sampling. Her intrepid searches narrowed down a list of prospective bakers to just two. After a couple of rounds of cake sampling, our bakers were confirmed and mandated.

Christmas cakes are aplenty in Malaysia. To cater to the largest swathe of the community, we decided to have both alcoholic and non-alcoholic cakes for sale.

To set the stage for something a little different we opted for rum as the base of our Christmas cake instead of the usual brandy. It was a great choice - the cake was moist, delicious, and smelled just heavenly.

For the non-alcoholic version, we opted for a recipe which used orange juice as its base.

Designing the Message

With that done, we got to work on our e-brochure, and Mrs Wong's designer came up with a few designs for us to choose from.

One of the silver linings of COVID-19 has been the groundswell of e-commerce, online banking, and purchasing. And thanks to that, our fundraising project caught on!

The e-brochure which was viral messaged as the herald of our fundraising project.

BOOK NOW !
Please call Julia
016 628 3950
(before 18 Dec 2020)

GIFTING FOR CHARITY
Yummy Christmas Cake for Sale!
Buy 1,2 or more for Christmas gifts for Family & friends

Rum Fruit Cakes
RM110 for 700 gm
Chock full of fruit,
nuts and generous
lashings of Rum

Luscious Fruit Cakes
Rm 80 for 600 gm
Chock full of fruit
Although contains no
alcohol - don't be
fooled! It will be love
at the first bite!

Another fund raising project by ASPAC
www.aspacmalaysia.org

Self Pickup or
Delivery by arrangement

Decorating the Cakes

To add a more festive touch to our finished product, volunteer Kar Im sourced beautiful red “Seasons Greetings” ribbons which could be wrapped around the cakes.

When the cakes were delivered by the bakers, industrious volunteers set to work and decorated the cakes with the ribbons, before repacking them into custom made, Christmas-themed bags.

These bags were designed and produced thanks to the generosity of Mrs Wong.



L to R: Sue, Lyla and Ms Gooi decorating the cakes with ribbons before repacking them into the custom-made bags.

Organising the Sales

Julia Choong was key in managing the orders and deliveries, which ran across the length, and breadth of the Klang Valley, and beyond.

She worked hard to take the orders, then sort the deliveries into manageable batches. While we did provide free delivery for the orders, some customers opted to collect their cakes from ASPAC directly.

Many thanks, Julia. We also thank our volunteer drivers Mr KH Ng and Mr KC Cheong for doing a fantastic job with their prompt and efficient delivery services.

Julia hard at work finalizing the orders and delivery schedules. At the back are cakes ready for delivery or collection.



The Outcome

We had an initial goal of selling 300 cakes; broken down into equal portions of 150 cakes of each type.

In the end, with the overwhelming response, we sold 382 cakes!

The Rum cakes were, by far, the more popular choice, of which we sold 231 cakes. As for the Luscious cakes, we sold 151 in total.

Our grateful thanks to all the volunteers who worked so tirelessly to make our efforts bear fruit. And, many, many thanks to all those who helped make this effort a success.

Here's wishing one and all a very Happy New Year 2021. We look forward to your continued support of our fundraising projects in 2021.

Editor: We thank Andrea for sponsoring two reams of Christmas ribbon.

RECEIVING WELFARE CONTRIBUTION FROM THE ARCHDIOCESE OF KL

By DR PATRICIA POR



Archbishop Julian Leow with recipients of the Selangor Government welfare contribution, nominated by and disbursed through the Archdiocese of Kuala Lumpur. ASPAC was represented by Dr Patricia Por.

The Archbishop of Kuala Lumpur Archdiocese, President of The Christian Federation of Malaysia (CFM) composed of three member organisations, namely the Catholic Church, Council of Churches and National Evangelical Christian Fellowship thanked the Selangor State Government for their generous gift of RM80,000 to each member organisation, totalling RM240,000 given in conjunction with the Christmas celebration on 21 December 2020.

ASPAC was one of 10 organisations nominated to receive a donation of RM8,000 from the Archdiocese. We are deeply grateful for this support and recognition of our work.

NEW APPOINTMENTS



Kumari Sathish joined ASPAC as Administrative Officer on 1 July 2020. She had worked at MEASAT Broadcast

Network Systems for 24 years before deciding to take up the VSS package and quit the media entertainment industry.

Her duties and responsibilities include overseeing office administration and human resource functions. Sathish is married with two grown-up sons.



We welcome back Palliative Care Nurse, **Masita binti Tan** who commenced work on 14 December 2020. Masita had previously worked in ASPAC before leaving ASPAC to once again work in Saudi Arabia. Upon returning to Malaysia thereafter, she worked in Cancer Research Malaysia as nurse navigator for a short stint.

Masita is an experienced nurse, having worked for many years as Senior Staff Nurse in King Faisal Specialist Hospital & Research Centre in Riyadh. She is a registered nurse with the Nursing Board of Malaysia.

DONATION FORM

NAME

NRIC / PASSPORT NO.

MOBILE NO. / HOME TELEPHONE NO.

EMAIL

ADDRESS

POSTCODE

Please accept my contribution of

RM30 RM60 RM90

Other amount: RM

I would like to contribute regularly as follows

Monthly Quarterly

Half-yearly Yearly

Starting from: _____ to: _____

Month Year Month Year

RM (in numbers):

RM (in words):

MODE OF PAYMENT

By cheque (Only for single donations.)
Cheque No: -----
Issuing Bank: -----

Bank Transfer (Only for single donations.)

Payee Details:

ASSISI PALLIATIVE CARE BERHAD
PUBLIC BANK A/C No: 31968057-28

By Credit Card (Visa/Mastercard)

Credit Card No:

Expiry Date: -----

Issuing Bank: -----

----- Date

Signature

DONOR SIGNATURE AND ACKNOWLEDGEMENT

I understand that by signing this Direct Debit Authorisation Form, I have read and understood the Terms and Conditions governing this Authorisation as reflected in the next section.

I also agree that my personal data provided is accurate and true, and consent to the collections, disclosure and use of this personal data by Assisi Palliative Care Bhd and its fundraising partners, the purpose of administration of this donation, in accordance with the Personal Data Protection Act 2010.

I consent to be acknowledged in publicity materials such as the annual reports, online platforms and event materials.

TERMS AND CONDITIONS

Direct Debit Donor Programme

Processing of the donations and the management of the database and donor communications is outsourced to <company name>. Your full donation will be 100% received by ASPAC. Each year, Assisi Palliative Care Bhd will allocate budget for various fundraising programme which includes Direct Debit Donor Programme, including the administration of this programme

Donation made by Debit or Credit Card

The first deduction will be made within 7 to 10 working days upon your signed acknowledgement of the Direct Debit Authorisation Form. Assisi Palliative Care Bhd will continue to charge the amount indicated above or the amount authorised by you to be deducted (which may differ from the amount indicated above) to your debit/credit card, so long as there is no change in the name of the cardholder and the debit/credit card number, unless and until the authorisation is terminated by you.

Cash Donation

This programme DOES NOT allow us to accept cash donations.

Personal Data

All personal data collected, used and disclosed under this Direct Debit Donor Programme is managed by Assisi Palliative Care Bhd and its fundraising partners, in accordance to the Personal Data Protection Act 2010.

We will use this information in order to:

- > administer your account with us;
- > process donations made by you and orders or applications submitted by you;
- > send you information and call you with regards to our events, programmes, services and fundraising;
- > verify your identity;
- > carry out donor profile analysis and make improvements to our organization's operations;
- > obtain your view or comments about our programmes and services; and
- > help us plan fundraising and/or other activities.

This authorisation will remain in force until terminated by written notice sent to Assisi Palliative Care Bhd, and upon receipt of your revocation in writing to Assisi Palliative Care Bhd or by phone call to Assisi Palliative Care Bhd and acknowledgement of the same.

Upon request, we will provide you access and will correct any error or omission in your personal data. No information, in whole or in part, in its paper or electronic format, will be disclosed, used, modified or reproduced for any other person or organisation, except in connection with these purposes stated.

Make a pledge today.

Be a Friend of ASPAC

RM30 is the minimum cost borne by us for visiting and treating ONE patient per day.



Left to Right: ASPAC Counsellor visiting a patient. | Touch Therapy for patient by ASPAC team members. | ASPAC Pet Therapy dog (Arthur) visiting a young patient at home.

Your kind contribution
will enable us to continue providing
quality hospice home care to our patients.

**Donation Form overleaf.*

About us...

Assisi Palliative Care Berhad (ASPAC) is a charitable, not-for-profit organization that provides hospice-at-home palliative care services covering areas up to 40 km in distance from our centre in Petaling Jaya, Selangor.

The home care team comprises of doctors, nurses, a counsellor and Volunteers and is supported by administrative staff.

We provide FREE care for patients with advanced cancer and for those with progressive non-cancer illnesses e.g end-stage organ failure, etc. Patients are accepted via referrals by the attending doctor.

Our mission is to empower people to live with dignity & hope whilst coping with illness & loss by providing quality medical care, spiritual and psychosocial support.