



ASPAC NEWS

VOL 4
January – June 2017

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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EDITORIAL

This fourth edition of AsPaC NEWS heralds the end of the second year of our provision of palliative care services to the Community.

With your assistance, we continue to grow with the addition of another doctor and nurse to extend our holistic care to all those in need, covering areas not included by other Hospices within a 40 km radius from our Centre. In 2016, we had 213 patient referrals from both government and private hospitals with a small percentage of referrals from GPs. Our medical team made 1873 home visits, whilst the counsellors and medical social worker made 352 and 93 visits respectively. Our volunteer visits increased from 61 in 2015 to 270 in 2016.

Apart from Petaling Jaya and the surrounding areas, our coverage includes Shah Alam, Kota Kemuning, Semenyih, Kajang, Sungai Long, Puchong, Subang, Sunway. A large proportion of our patients live in the Kajang area. As such, we do hope to recruit a palliative care nurse and more volunteers living in that area as it would reduce distances travelled by the current Team and enable us to extend our services to other areas.

Our grateful thanks to all the staff and volunteers for doing a great job. We also wish to thank all our benefactors for their donations and continual financial support to enable us to provide services free of charge to our patients.

Thank you and happy reading.



Dr Patricia Por
Chairperson,
Board of Directors

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THE WINDMILLS OF MY MIND by Mr AK Sabapathy

I pass this way only once
I had loved and lived in moderation
Any good that I could do, I had done
Any kindness I could show, I had shown

Regrets, I have few
My happiness and grief are results of my doings
I am not penalised for my anger
I am punished by my anger

My temple is my conscience
My religion is my service without harm
I do not ponder on what I had done
I seek what remains to be done

I have an insatiable crave for knowledge
I live as if there is no tomorrow
My desire is to pass on to the next phase of life's journey with dignity
I do not fear death

In prayer, I am grateful, thankful for the gift of my eventful beautiful life
I seek forgiveness for my omissions and errors

My journey ends here
I shall not pass this way again.

Not many people are aware of the significance of an Advance Medical Directive (AMD). Here, Mr Sabapathy has kindly consented to allow us to share with our readers a copy of his for information purposes.

To know more about AMD, please refer to 'What Are Advance Medical Directives' in this newsletter.



Mr Sabapathy in a good mood.

DO-NOT-RESUSCITATE ORDER

I have had a good life and I have done my duty to the best of my ability and knowledge. When my time is up I would like to happily accept the call and peacefully leave this world.

I request that in the event my heart and breathing should stop, no person shall attempt to resuscitate me.

Under any circumstance I do not want performed or administered on me any specific procedures such as:

CPR (if cardiac or respiratory arrest occurs)
Artificial nutrition through intravenous or oro-nasal tube feedings
Maintenance on a respirator (if unable to breathe adequately)
Blood cultures, and any body fluid evaluations, and other diagnostic tests
Blood transfusion
Tracheostomy and any other procedures.

Being of sound mind, I understand its full importance and I voluntarily execute this order.

This order is effective as of to day.


Declarant's signature

Date - 8 APR 2016

Declarant's name and IC Number) A.K. Sabapathy a/k K.B. Appan
290615-08-5227

ATTESTATION OF WITNESSES

The individual who has executed this order appears to be of sound mind, and under no duress, fraud, or undue influence.


Witness name: KARAM SINGH

Date - 8 APR 2016

No. 26A, Jalan Yang Shook 118
16200 Petaling Jaya (D/A) 45110 'Eaves'
Selangor Darul Ehsan


20/10/2016

IN MEMORY OF MY LOVING MOTHER by Lena Khaw

My mother, Lim Swee Yin was born in Mambau, a small town in Negri Sembilan in 1919. She had Peranakan roots and was raised to put “family first”. She was baptised Anna only in 1985 after recovering from a stroke.

Though her formal education was rudely interrupted by the Japanese Occupation, like all mothers, she wanted her three children to be much better off than herself. She worked hard to save. During Chinese New Year she made *Nonya* cookies to earn extra money so that when we went to further our studies in other towns for Form 6 or University, she was able to buy us motorcycles for our transportation.

She had been fairly healthy until the age of 60 when she had an extensive stroke which affected the right side of her body. Whilst it impaired her speech, she recovered physically, and her movements improved through constant and daily exercises. She wanted to get well so much. She supervised the maid and looked after her 3 grandchildren after that.



The late Madam Lim Swee Yin

Age related maladies then started to creep up on her. She had a fall and had a hip replacement in her 80s. Her determination to be independent helped her adapt herself to a Zimmerman frame. What was most debilitating was the Restless Leg Syndrome which affected her sleep patterns. Even though going for regular check-ups involved long waiting times, she was happy for those “outings”. Her body was a pharmacy of medication for all her ailments. She was however still able to enjoy her food with just bouts of listlessness and loss of appetite. As she progressed to her nineties, her speech ability worsened. That frustrated her greatly and reduced her to episodes of tears.

In early 2016 however, we noticed a change. She wanted to go to the hospital, but couldn’t tell us why she wanted to do so. One day we noticed she couldn’t lift her left arm. She had lost control of her right arm. The stroke had left a permanent damage to her speaking ability, but now we noticed that her mind was foggier and she had lost control of her right arm. We suspected she had another mini stroke that came on very slowly and surreptitiously. She had difficulty swallowing. That started a downhill trend of her health and subsequently her will to live. By July 2016 she was reduced to skin and bones. We couldn’t watch her fade away.

A church friend suggested we contact AsPaC for help. Soon Dr Lalitha and her team came to assess my mother and from then on their visits to check on her became fairly regular. We were able to call them if we faced problems and they would always respond. When we were at crossroads in making decisions, their Counsellor, Sr Kristin, would counsel us to take one day at a time and to make my mother as comfortable as possible. She advised us to bring her for walks in the park for fresh air and a change of environment. When she couldn’t swallow, the team would recommend a blended diet of all kinds of potatoes and vegetables and protein, ice-cream, milk drinks and yogurt, all given in morsels according to my mother’s ability to swallow. The nurses who attended to her were the most gentle and loving. They undertook the meanest of tasks just to make my mother comfortable. Nurse Roohini was a gem. Sr Ong brought in the Ripple Mattress and fixed it up for her to prevent bed sores that were forming.

We were taught to care for our mother the way she should be cared for in the last days of her life. We never thought that she would leave us so soon because she had always been a fighter and she always suffered a lot before things changed for the better. She had survived 8 falls, had a pelvic joint replacement and learnt to walk with a frame. So, when she breathed her last on the night of Dec 21 at 9.40, it came as a shock. It was just a few days after Nurse Ong had fixed up the Ripple Mattress for her, and confirmation of her X-ray had come to say that it was not pneumonia as earlier suspected. The

day before she passed on, despite her frailty and uncertain that she'll be able to enjoy the air and sunshine in the park, I took a chance and propped her in her wheelchair and we completed 3 rounds. While she could not lift her head up (she was so weak now), she was able to open her eyes to see what she could see. She was tired, just so tired.

At 97, she had given the best of her life to us; the 3 children and the grandchildren. We hope we have given our best to her at least in the last 6 months of her life. We thank AsPaC for rendering palliative care and ensuring a peaceful journey for our mother Anna Lim Swee Yin. Finally, our mother has been granted perpetual peace, freed from suffering and pain.

MY GRANDSON, KUAN LING by Chung Ah Chin

My grandson, Kuan Ling suffered from tibia osteosarcoma. He was only 17 years old when he passed away. His grandmother and I were fortunate to be able to care for him when it was decided that he come to live with us.



Kuan Ling was always calm and smiling despite his illness. He never shed a tear.

For the whole 39 days that he was with us, we did our best to give him comfort and share with him Buddha's teachings to the best of our ability. We had daily chantings and I taught him the Dhamma suttas. I told him that if he were to feel scared or uncomfortable, he could chant Amitabha holding the prayer beads. Soon, the prayer beads became a source of comfort for Kuan Ling.

Kuan Ling passed away peacefully with his mother and I by his side. We were doing chanting and at that time and I thought I heard other voices chanting as well, softly and peacefully. And then, we noticed that his face became more serene and good looking. We were very happy that he was not in pain during his final moments.



Kuan Ling's grandfather

My family and I are most grateful for the care given to Kuan Ling and would like to thank Dr Lalitha, Sister Kris, Ms Ong, Sharon, Mashita and all the nurses at AsPaC.

FREEDOM

*Let us learn to be free,
And not entangle ourselves in worldly bondage,
Looking at Death as a fearsome thing,
Sickness as intolerable, Old age as unapproachable,
Poverty as unthinkable,
But learn to face these four elements,
And overcome them...*

MOTHER MANGALAM

EDUCATIONAL & TRAINING ACTIVITIES

Volunteer Training Workshop – March 2017

A Volunteer Training Programme was held on 2 March 2017 at the Assumption Family House. The training programme was facilitated by Dr Lalitha Jeyasingam (Medical Director, AsPaC), Ms Ong Swee Ee (Senior Palliative Care Nurse) and Sr Krisna Muthusamy (Palliative Care Nurse Tutor). The turnout was very encouraging and the volunteers' active participation made it a very meaningful and successful training session. Role plays were conducted to simulate the actual scenarios when attending to patients and proved to be an effective learning process. One of our Directors also attended the training programme.



Role play session...



Nurse Ong conducting one of the training sessions.

Hands-on Training with Sr Krisna

Sr Krisna Muthusamy, Palliative Care Nurse Tutor from Penang spent three weeks at AsPaC recently to share her experience and knowledge with our medical team.



Sr Krisna Muthusamy (second from right) with the AsPaC team

Sr Krisna has vast nursing experience gained from her nearly 20 years working abroad. She had served in many medical establishments and has many years of palliative care experience under her belt.

Our medical team benefitted greatly from her visit here and we are most grateful to Sr Krisna for sharing her invaluable knowledge and time with us.

Clinical Training - Hand Massage Therapy

Our palliative care nurses, Kam Yong and Roohini practising hand massage therapy. A clinical training session was held to share the knowledge and skills/approach for hand massage therapy.

Our patients have benefited from receiving hand massage therapy as it relaxes them and gives them comfort.



RAISING AWARENESS

On 26 February 2017, AsiaWorks Foundation held their annual blood donation campaign. AsPaC was once again invited to participate in this event (2nd year in a row). The objective was to create awareness in regard to palliative care and the services offered by AsPaC.

Our Medical Director, Dr Lalitha gave a talk to the donors and the public about palliative care and we managed to disseminate quite a number of our brochures and newsletters to the public. We received many enquiries in regard to our services as well. All in, it was a successful event and we would like to extend our gratitude and thanks to AsiaWorks Foundation for having us there and supporting our endeavours.



Staff and volunteers at Asia Works Foundation to raise awareness of AsPaC in February 2017

APPRECIATION



*Our patient giving a very cheerful “Hi!”.
He was so happy to see Dr Lalitha and Sr Kristin
when they visited him at the hospital.*

*Sr Kristin is feeding him some light food in this
photo.*

*Our Palliative Care Nurse, Ms Satwin,
showing our patient the artwork of her
family's palm prints.*

*As they say, “A picture paints a thousand
words”. Therefore, we at AsPaC turn to
art to help strengthen family ties during
these difficult times.*

*This photo was later framed and given to
the family as a remembrance.*



*In appreciation of their wonderful work and
to celebrate International Women's Day,
the AsPaC team was treated to an
appreciation lunch organised by Dr
Lalitha.*

*It was indeed a rare occasion that all the
staff were able to gather together for a
delicious meal at the famous food court in
PJ Old Town.*

WHAT ARE ADVANCE MEDICAL DIRECTIVES?

In Malaysia, there is currently no legislation or judicial pronouncement in regard to Advance Medical Directives (unlike in Singapore). It is however supported by statute such as the Mental Capacity Act 2005, SS 25-27 and have been recognised by the Courts.

With the advancement of medical technology, doctors now have the ability to prolong a patient's life through life - sustaining treatments. However, at the end of the day, every adult has the legal right to consent to or refuse medical treatment and may declare their wishes in writing in the event that they cannot communicate them. This legal document is called the Advance Medical Directive.

The following article extracted from the Mayo Clinic website explains very clearly what AMD is all about. Certain sections not relevant to the Malaysian scenario have been omitted but that does not in any way change the gist of the article. We hope you find the article informative.

Article extracted from Mayo Clinic's website.

LIVING WILLS AND ADVANCE DIRECTIVES FOR MEDICAL DECISIONS

Living wills and advance directives describe your preferences for end-of-life care. These documents speak for you when you're not able to speak for yourself.

Living wills and other advance directives are written, legal instructions regarding your preferences for medical care if you are unable to make decisions for yourself. Advance directives guide choices for doctors and caregivers if you're terminally ill, seriously injured, in a coma, in the late stages of dementia or near the end of life.

By planning ahead, you can get the medical care you want, avoid unnecessary suffering and relieve caregivers of decision-making burdens during moments of crisis or grief. You also help reduce confusion or disagreement about the choices you would want people to make on your behalf.

Advance directives aren't just for older adults. Unexpected end-of-life situations can happen at any age, so it's important for all adults to prepare these documents.

Power of attorney

A medical or health care power of attorney is a type of advance directive in which you name a person to make decisions for you when you are unable to do so.

The person you name may be a spouse, other family member, friend or member of a faith community. You may also choose one or more alternates in case the person you chose is unable to fulfil his or her role.

Choosing a person to act as your health care agent is important. Even if you have other legal documents regarding your care, not all situations can be anticipated and some situations will require someone to make a judgment about your likely care wishes. You should choose a person who meets the following criteria:

*Meets your state's requirements for a health care agent
Is not your doctor or a part of your medical care team
Is willing and able to discuss medical care and end - of life issues with you
Can be trusted to make decisions that adhere to your wishes and values
Can be trusted to be your advocate if there are disagreements about your care*

Living will

A living will is a written, legal document that spells out medical treatments you would and would not want to be used to keep you alive, as well as other decisions such as pain management or organ donation.

In determining your wishes, think about your values, such as the importance to you of being independent and self-sufficient, and what you feel would make your life not worth living. Would you want treatment to extend life in any situation? Would you want treatment only if a cure is possible?

Have discussions with your primary care doctor, your health care agent, family and friends about your personal wishes.

You should address a number of possible end-of-life care decisions in your living will. Talk to your doctor if you have questions about any of these issues:

Resuscitation restarts the heart when it has stopped beating. Determine if and when you would want to be resuscitated by cardiopulmonary resuscitation (CPR) or by a device that delivers an electric shock to stimulate the heart.

Mechanical ventilation takes over your breathing if you're unable to do so. Consider if, when and for how long you would want to be placed on a mechanical ventilator.

Tube feeding supplies the body with nutrients and fluids intravenously or via a tube in the stomach. Decide if, when and for how long you would want to be fed in this manner.

Dialysis removes waste from your blood and manages fluid levels if your kidneys no longer function. Determine if, when and for how long you would want to receive this treatment.

Antibiotics or antiviral medications can be used to treat many infections. If you were near the end of life, would you want infections to be treated aggressively or would you rather let infections run their course?

Comfort care (palliative care) includes any number of interventions that may be used to keep you comfortable and manage pain, while abiding by your other treatment wishes. This may include being allowed to die at home, getting pain medications, being fed ice chips to soothe dryness, and avoiding invasive tests or treatments.

Organ and tissue donations for transplantation can be specified in your living will. If your organs are removed for donation, you will be kept on life-sustaining treatment temporarily until the procedure is complete. To help your agent avoid any confusion, you may want to state in your living will that you understand the need for this temporary intervention.

Donating your body for scientific study also can be specified. Contact a local medical school, university or donation program for information on how to register for a planned donation for research.

Do not resuscitate and do not intubate orders

You don't need to have an advance directive or living will to have 'do not resuscitate' (DNR) and 'do not intubate' (DNI) orders. You can make your preferences known to your physician, who can write the orders and put them in your medical record.

If you have a living will, however, be sure to mention it, whether you have a DNR or DNI order on file.

Creating advance directives

Advance directives need to be in writing and may need to be signed by a witness or notarized. You can ask a lawyer to help you with the process, but it is generally not necessary.

Review your advance directives with your doctor and your health care agent to be sure it has been done correctly. When you have completed your documents, you need to do the following:

Keep the originals in a safe but easily accessible place.

Give a copy to your doctor.

Give a copy to your health care agent and any alternate agents.

Keep a record of who has your advance directives.

Talk to family members and other important people in your life about your advance directives and your health care wishes.

Carry a wallet-sized card that indicates you have advance directives, identifies your health care agent, and states where a copy of your directives can be found.

Keep a copy with you when you are traveling.

Reviewing and changing advance directives

You can change your directives at any time. If you want to make changes, you must create a new one, distribute new copies and destroy all old copies.

You should discuss changes with your primary care doctor and make sure a new directive replaces an old directive in your medical file. New directives must also be added to medical charts in a hospital or nursing home. Also, talk to your health care agent, family and friends about changes you have made.

You should consider reviewing your directives and creating new ones in the following situations:

- *New diagnosis. A diagnosis of a disease that is terminal or that significantly alters your life may lead you to make changes in your living will. Discuss with your doctor the kind of treatment and care decisions that might be made during the expected course of the disease.*
- *Change of marital status. When you marry, divorce, become separated or are widowed, you may need to select a new health care agent.*
- *Change in wishes. Over time your thoughts about end-of-life care may change. Review your directives from time to time to be sure they reflect your current values and wishes.*

NEW STAFF

DR TEH EE VON

Dr.Teh is a graduate of the International Medical University (IMU), Kuala Lumpur. She has 10 years' work experience in Emergency and Family Medicine, is also a certified Occupational Health Doctor and has a keen interest in the field of palliative care. She joined us in February 2017 as Medical Officer and has proven herself to be a committed and enthusiastic doctor.



KONG KAM YONG



Kam Yong holds a Diploma in Nursing and Advance Diploma in Oncology from Nanyang Polytechnic, Singapore and Bachelor of Health Sciences from the University of Sydney. She has 10 years of nursing work experience in Internal Medicine, Haematology and Oncology Departments at Singapore General Hospital. Following a stint in HCA Hospice Care in Singapore, she returned to Malaysia in 2014 and served in various Palliative Care Organisations.

Kam Yong enjoys working in home care because - in her own words - "It is holistic care and I feel satisfied...it is very fulfilling". She joined us in March 2017 as Palliative Care Nurse.

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 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.