



# HOSPICE Bulletin



National  
Cancer  
Society  
Malaysia  
PENANG BRANCH

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Quarterly newsletter of the National Cancer Society of Malaysia, Penang Branch.

## PALLIATIVE CARE IN MALAYSIA LACKS ENVIRONMENT OF SUPPORT

*By Dato' Seri Dr T Devaraj*

The January issue drew attention to the reality that of those patients who need palliative care hardly ten out of a hundred or 10 percent get this help, be it in the home or in a hospital. Ian Maddocks, who was appointed chair of palliative care at Flinders University, Australia in 1988– the first in the world - said an environment of support was needed for the delivery of palliative care. Our experience of providing palliative care in the homes of seriously ill patients over three decades points to a lack of a supportive environment thus making it much harder for voluntary service providers in Malaysia.

What do we mean by supportive environment? Take for instance the advice that exercise is of health benefit for everyone. In urban areas, where almost eighty percent of us live, are there adequate physical facilities such as pavements, open spaces, playgrounds, cycle tracks for people to exercise? Thus to facilitate palliative care delivery, say, in the community, requires suitable mind sets, adequate structures and funding. These are lacking. In health what prevails is a focus on institutional care, be they hospitals or clinics with no provision for care at home. This is despite the fact that Malaysia is a signatory to the "Health for All" declaration at Alma Atta in 1978 and which was reinforced in the declaration in October 2018 at Astana in Kazakhstan namely, that health care is founded on primary care. Thus a primary care-led health system has a family doctor as the first contact, with referrals if necessary to hospitals who coordinate care in the community including care at home. All developed countries follow this system. Why this is not practiced Malaysia is a question awaiting an answer.

Though the health care system is not geared for care at home, the voluntary hospice movement has shown the way – that medical care at home can be done, it helps and is economically viable. The pressure for home care has been growing all over the world for decades. It is a direct consequence of an ageing population and the continuing increase of chronic diseases such as diabetes, hypertension and cancer. Another group is the neurodegenerative diseases, especially dementia for which there is no cure. Ironically advances in medical knowledge and technology in recent years have led to more ill people surviving (which is good) and a temporary postponement of death. The global reality is more and more people are living longer but with some impairment of health - from disease or just being frail. So the need now is long term care. Society has to decide who needs care, what kinds of care, where (home, hospitals, residential or nursing homes) it can be provided, who will provide such care and how will it be financed. Each country has to find answers and make the necessary structural changes and set aside resources.

That we will need more money for health and health care is a given. Health care costs in Malaysia now are about sixty billion ringgit annually, shared equally between the public and private sectors. A worrying feature of costs in the private sector is out-of-pocket spending by the public which is about forty percent – which could mean that health care costs for some families can be an overwhelming

burden. Reports from the United States of America have for some years indicated not only a rise in bankruptcy but this is directly due to health care costs. Health care costs in Malaysia in terms of the GDP is about 2.1 percent for the public sector and about two percent for the private sector. This figure of about 4.1 percent is well below WHO's advice of 7-8 percent.

The PH government had a plan to raise the public sector share to six percent. Though not in power now, at long last a need has been acknowledged. We are not the only country that needs more ringgit for health care. Thanks to Covid-19, a lot of countries, developed and developing, have come to realize this reality. All countries have to choose between more spending on health and at the same time meeting the challenge of climate change – which has been already labelled as a far worse calamity than the current pandemic. Is there enough money in the world for both? Of course there is – just reflect on the billions of dollars spent a year on armaments. Malaysia is no exception. Will common sense prevail?

If we want palliative care needs to be adequately addressed in Malaysia paradigm shifts in thinking must occur first and soon. The onus is on the medical profession, the government and the public. Who will take the FIRST step?

## Contents:



## HAPPENINGS:

### • CARERS' MEETINGS\_Penang Island

**Venue :** Rumah Hospis Pulau Pinang  
**Day :** Every Thursday  
**Time :** 0900 - 1100

### • CARERS' MEETINGS\_Seberang Perai

**Day :** Every Friday via zoom  
**Time :** 0900 - 1100

### • CARERS' MEETINGS with Dr Jaishree

**Once a month via zoom**  
**Time :** 1400 - 1600

## About Hospice Bulletin

**HOSPICE BULLETIN** is the quarterly newsletter of the National Cancer Society of Malaysia, Penang Branch with input from Penang Hospice Society. Please submit at least six weeks before issue date which are the first day of January, April, July and October.

All items submitted for inclusion in the Hospice Bulletin must be signed but author's requests to remain anonymous will be respected. Contributions can be sent to: The Editorial Team, National Cancer Society of Malaysia, Penang Branch/ Penang Hospice Society, 250A Jalan Air Itam, 10460 Penang.

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The views expressed in HOSPICE BULLETIN are not necessarily those of the National Cancer Society of Malaysia, Penang Branch, the Penang Hospice Society or of the Editorial team.

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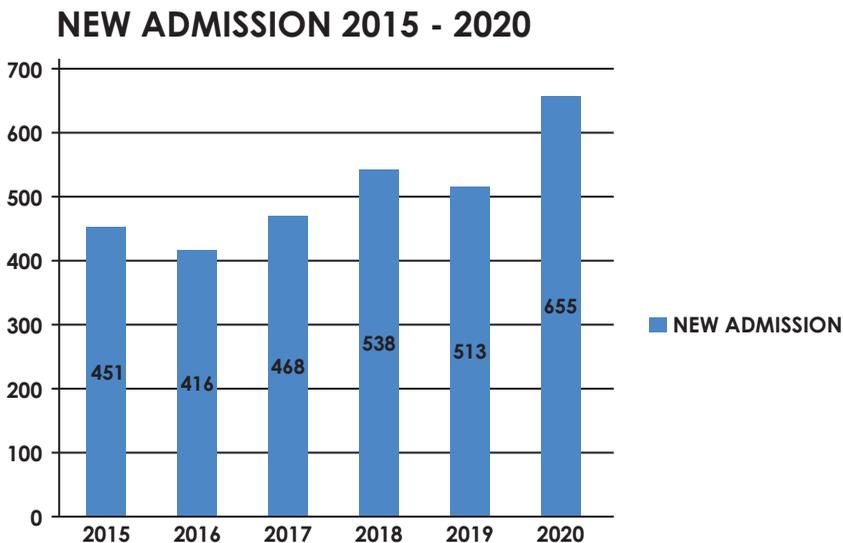
# HOSPICE AT HOME PROGRAMME 2020

By Dato' Seri Dr T. Devaraj

What a year it has been for all of us and our hospice at home programme. It was challenging and we are thankful that both the patients and our staff have kept well. With public health measures generally taken to heart by the public and Covid-19 vaccination set to take off by the end of February we can see light at the end of the tunnel. Hopefully 2021 will be a new dawn. In Malaysia, the dawn should to rectify the many shortcomings highlighted by the pandemic. Some aspects of care delivery are briefly discussed.

## ADMISSIONS

The upward trend of new admissions continued in 2020 as the following chart indicates. With a carryover of 224 patients from 2019 patients looked after in 2020 was 879 compared to 707 in 2019.



## VISITS

With travel restrictions in place intermittently the total number of visits was 7907 (8958 in 2019). Visits by nurses dropped to 6563 from 7431 last year and similarly visits by doctors showed a drop to 803 compared to 881 last year. But bereavement visits went up to 425 (385). As expected there were less visits to see patients in hospital being 116 this year (260). However telephone calls increased from 9197 to 10,904.

## REFERRALS, PLACE OF DEATH AND PERIOD UNDER CARE UNTIL DEATH, NON-CANCER

While family referrals of about eight percent remained the same there was significant change in referrals from the palliative care units at Hospital Pulau Pinang and Bukit Mertajam of 17% (11.5%). This indicates a close working relationship. There were more deaths at home, namely 72% (62%). The figures for the period of care in the programme showed significant changes in that just short of 34% died within ten days compared to about 26% last year. That late referrals is seen in many programmes, not only in Malaysia but also globally, is a continuing issue of attitudes, both professional as well as the public. Last year non-cancer admission increased to about 15%. In developed countries it is about a third.

If this upward trend of admissions of cancer and non-cancer patients continues, the programme implications will arise and we have to plan accordingly. The time is ripe for a closer look at how care delivery can be augmented by Information Technology so conserving our resources while at the same time assuring that good quality care is provided in the homes of the patients.

# PROJECT ECHO

## Moving Knowledge Instead of Patients and Providers

ECHO stands for Extension (for) Community Healthcare Outcomes. It is an education and training project sponsored by the Malaysian Hospice Council with the help of University of Malaya and the Ministry of Health. The objectives are to enhance knowledge and competencies of palliative care providers nationally through case-based discussions and didactic presentations, enabled dialogue, engagement, sharing and learning of best practices between palliative care providers, promoting palliative care delivery and improving patient care outcomes.

It came about in 2003 from the vision of Dr Sanjeev Arora, a specialist in diseases of the liver at the University of New Mexico Health Sciences Centre, Albuquerque, New Mexico. He was frustrated that he could only help a few Hepatitis C patients though there were many more patients in the community who needed help. So he created a free educational model and mentored community providers across New Mexico on how to treat these conditions. This mode of mentoring took off in the US and till now had spread to forty - five countries.

The following charts spell out the mission, principles and locations globally.

### MISSION



# PRINCIPLES

## Principles - ABCD

Community EMPOWERMENT through

**A**mplification - Use **T**echnology to leverage scarce resources



**C**ase Based Learning to master complexity

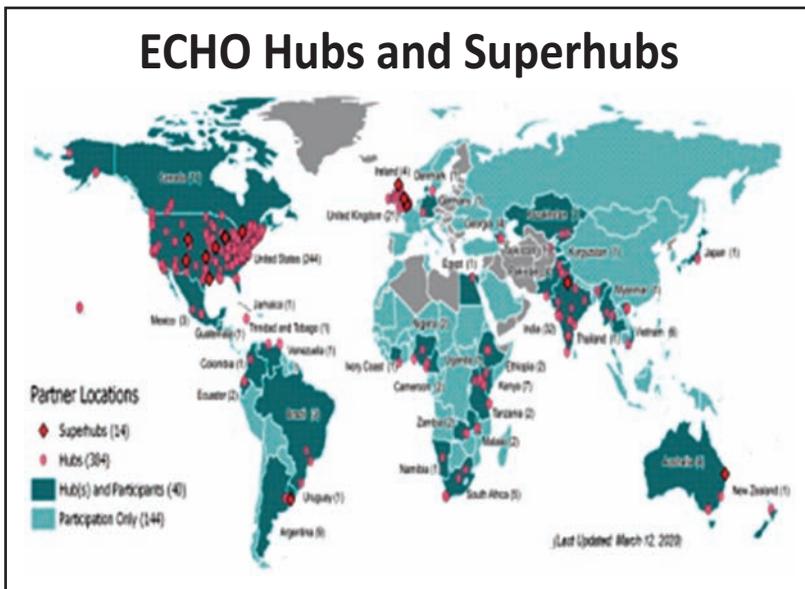
Share **B**est Practices to reduce disparity

Web-based **D**atabase to Monitor Outcomes

Demonopolize knowledge - ALL Teach, ALL Learn!

# LOCATIONS

## ECHO Hubs and Superhubs



It should be noted that this is not akin to telemedicine where a specialist assumes care of the patient. Here telementoring is a guided practice model where a participating clinician retains responsibility for managing the patient. This project has the ambitious goal of touching one billion lives by 2025.

The ECHO project was initiated in late 2020 biweekly. Thus far there has been four meetings with topics being : What is palliative care; running a hospice organisation; managing intestinal obstruction at home and assessment; and management of pain along with case presentations by hospice societies. PCN Molly Lim of the society presented a patient with intestinal obstruction on 5th February.

An interesting development in some countries is that the ECHO model has been adopted in other domains such as education and social issues.

## The National Cancer Society Programme 2020

The National Cancer Society of Malaysia, Penang Branch kick-started a program for 2020 with Bubble Wild Day with FOCCAN & Families. The program was jointly organized by Rainbows Kids Club on 2nd February 2020 (Sunday) at Rumah Hospis Pulau Pinang. The event took place from 09.00am to 12.00pm engaging the parents and kids from Persatuan Kanak-Kanak Kanser Wilayah Utara (FOCCAN). Program activities included ice breaker dance, bubble play and art, games and little chef fun. The event marked the second-year collaboration between NCSM Penang Branch, Rainbows Kids Club, and Persatuan Kanak-Kanak Kanser Wilayah Utara (FOCCAN).

Besides the program for cancer children, NCSM Penang also participated in the Exhibition on Health and Safety (EHS) organized by NI Malaysia Sdn Bhd, Batu Maung on 6th February 2020. This campaign was aimed at raising awareness about cancer and to promote our Etiqa Free Mammogram. On 1st March, NCSM Penang was once again invited to set-up a cancer awareness booth to support the World Cancer Day program organized by Penang Adventist Hospital. The event took place at Pusat Agro Pelancongan Pulau Pinang Man Man Market, Relau.

As you know, because of Covid-19 pandemic, Prime Minister Tan Sri Muhyiddin Yassin had officially announced the movement control order (MCO) on 16th March 2020. This has changed the landscape of how NCSM Penang used to run its program. Most of the event invitations had been canceled which included the annual event Relay For Life Penang. Most of the events shifted to virtual platform including NCSM #StaySafeAndRun and series of cancer webinars.

During the Recovery Movement Control Order (RMCO) period, NCSM Penang had participated in the Bazar Bangkit Bersama - Tesco Hari Merdeka Buy For Good Bazaar to set-up a cancer awareness booth at Tesco Bukit Mertajam on 22nd & 23rd August 2020. This CSR project was organized by Epiq Events Solutions mainly to support NGOs to promote and sell their product and services to the public as an effort to raise their funding after the pandemic.

Sambutan Pink October Peringkat Klinik Kesihatan Air Itam was the last on-site event NCSM Penang had participated in. The event was held on 7th & 8th October at Klinik Kesihatan Air Itam. The event included a cancer awareness booth, a breast-self exam demo, and survivor's sharing by Mdm Shakirah Md Din - a breast cancer survivor. The first webinar of NCSM Penang was on 21st October titled "Psychological and Emotional Aspects of Cancer" given by Dr. Aishah Knight. The webinar was initiated by Human Dynamic - a consulting agency.

In the first quarter of 2021, NCSM Penang was once again invited to partner with Human Dynamic to share knowledge on cancer with their clients. Under their caregivers for cancer patients group coaching program, three webinar series with the title "Understanding Cancer" by Dr. Saraswathi Bina Rai is scheduled on 9th February, 9th March, 30th March 2021. On 20th February 2021, NCSM Penang was given an opportunity to talk in a webinar program "Let's Talk Cancer Awareness" to UOW Malaysia KDU Penang University college students.

NCSM Penang is committed to providing public information, education, and early detection of cancer. If you're interested in one of our programs, please contact our office for arrangement.



Buble Wild Day FOCCAN & Families 27 Feb 2020



Exhibition On Health & Safety 6 Feb 2020



World Cancer Day 2020 1 Mar 2020



Bazar Bangkit Bersama - Tesco



Food Bank Donation 2020



Sambutan Pink October 2020



# Practical support from a Lay Volunteer's point of view.

## By Mrs Siok Phang, lay volunteer of Hospice-at-Home Programme

A companion can be a source of encouragement, sympathy and tireless assistance.

'When she couldn't walk to the toilet, I was her spine, when she despaired,  
I was her hope, when she needed peace  
I was her guardian'

- Anonymous -

This was in 1992 and after receiving basic training in Hospice Work we, the Lay volunteers, were let loose on the unsuspecting patients.

Each patient in those days had a doctor, a nurse and a Lay volunteer assigned to him/ her; I'm talking from a Lay volunteers point of view and would like to touch on the practical support that a Lay volunteer can give to the patient, of course the longer you have with the patient the better is the support with the patient the easier it is to help or give practical support.

Even if you have no medical training and no basic nursing, practical support can be given to both patient and family members. Of course some medical terminology will rub off on you e.g. PRN – Pain Relief Never? No, No! PRN = When necessary!

DOA – Dead On Arrival? Too many Medical / Cop

Sit – coms!

DOA = Date of Arrival!

Seriously, all you need is to be Alert, Observant and Willing to help. Don't force your help, just offer it, when visiting. Don't do what you cannot do. Don't take on 3 patients when you can only manage 1. In some instances help can be given without even the patient or carer being aware of it. E.g. once we swept the porch and got rid of all the fallen mango leaves and dead flowers before the patient even opened the front door.

These are just a few ways practical help can be given to a patient.

- Preparing a drink for the patient. But be certain to ask what the patient would like and not say "This or that is good for you".
- Doing simple household chores e.g. washing dishes, ironing, marketing
- Taking the patient for hospital appointments or just for a drive
- Contacting friends, family members, religious leaders
- Introducing distraction therapy / hobbies

Practical help can also be given to the carer or family members:

- Giving carer time off to do what he/she needs to do
- Giving help in your field of expertise whether you are a housewife, Lawyer, Teacher etc.
- At time of death – help by accompanying carer to the police station to report the death; to the newspaper office to put in an obituary, phone a reliable casket company who will do the necessary; provide food.

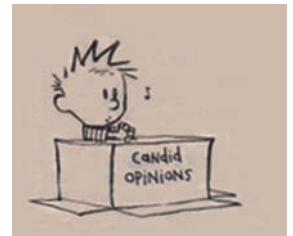
But when the relatives arrive allow them to take over. Don't be upset if you are forgotten. Quietly slip away. However your role does not end here as you may have to make several bereavement visits to support the family through their grief.

These are just some ways of practical support. I am sure you can add to them.

It is good to remember that giving support or care whether it is spiritual, psychosocial or practical is giving what the patient and family need and not what you HAVE or WANT to give. Remember also that a patient is treated as you would treat your own loved ones.

Finally don't give up being a volunteer as Calvin said in the "Calvin and Hobbes" cartoon by Bill Watterson.

(This article was first published in the 25th anniversary book)



## **By Puan Hjh. Suriati binti Saat – Balik Pulau – wife of Encik Roslan, Hospice-at-Home Programme patient**

Kring...kring...kring...Hello.....bagai halilintar membelah bumi, bagai letupan gunung berapi...begitulah pertama kali aku rasakan tak kala menerima panggilan telefon menyatakan suamiku yang tercinta Roslan bin Abd Majid ditimpa musibah pada pagi 4 April 2016 yang lalu. Aku tergamam, terkejut tetapi aku kuatkan semangat dan terus membawa anak-anakku ke hospital. Dalam perjalanan aku tak henti-henti berdoa. Aku pasrah dan doa terus berkumat-kamit di bibirku bersama air mata yang berlinangan.

Sesampai saja aku di hospital, aku dimaklumkan tentang kondisi suamiku. Tanpa berfikir panjang aku serahkan segalanya di tangan pakar-pakar neurologi yang arif. Akhirnya suamiku selamat dalam pembedahan yang serius. Alhamdulillah. Aku redha dengan ketentuan ilahi. Suamiku masih separuh sedar sehingga kini. Mulanya aku serba tak kena, resah dan sukar dalam menguruskan suamiku. Berat mata memandang berat lagi bahu yang memikul.

Selepas sebulan suamiku dibenarkan pulang ke rumah. Ramailah kenalan, sahabat handai dan kaum keluarga yang datang menziarah. Aku mendapat tahu dari seorang rakan tentang Hospice. Aku pun mengambil langkah yang pertama. Aku menelefon ke sana dan disambut dengan layanan yang mesra dan sopan. Selang beberapa hari, datanglah dua orang jururawat untuk memantau suamiku. Cik Subaahsini jururawat yang melaporkan kes suamiku kepada panel Hospice. Alhamdulillah suamiku diambil sebagai pesakit mereka.

Walaupun pihak Hospice banyak membantu pesakit-pesakit kanser, namun mereka tidak meminggirkan pesakit yang lain. Jururawat silih berganti Cik Subaahsini melanjutkan pelajaran dan diganti oleh Puan Logeswery. Setiap minggu pihak Hospice akan datang membuat lawatan ke rumah. Jururawat-jururawat ini sangat baik dan banyak membantu. Mereka banyak memberi tunjuk ajar dan menunjuk cara untuk menjaga pesakit dengan betul. Bibirku dari tidak mengerti untuk menguruskan suamiku, kini menjadi lebih arif setaraf jururawat yang bertauliah.

Puan Logeswery pula meninggalkan kami untuk bertugas di Kuala Lumpur. Terima kasih Puan Logeswery jasamu dikenang. Walaupun demikian segala tugasan dan tunjuk ajar tetap diteruskan pula oleh Puan Ann. Setiap minggu pihak Hospice akan datang melawat dan membekalkan barang keperluan seperti ubatan yang terdapat dalam simpanan mereka. Terima kasih Hospice. Jururawat-jururawat Hospice sangat mesra dan boleh dianggap seperti keluarga sendiri. Pihak Hospice banyak membantu saya dalam melancarkan proses penjagaan yang rapi terhadap suami saya.

Terima kasih yang tidak terhingga diucapkan kepada pihak Hospice. Saya berharap agar bantuan dan bimbingan seperti ini dapat diteruskan lagi.

Pergi ke kedai membeli benang,  
Jarum tercucuk terkena jari,  
Jasamu Hospice tetap dikenang,  
Tersemat abadi di sanubari.

Pergi mencari si daun mempelas,  
Ke kaki bukit di hujung tanjung,  
Budi yang luhur akan dibalas,  
Ke akhir hayat baktimu disanjung.

(This article was first published in the 25th anniversary book)

# A Tribute

*By Regina Malayapillay & family*

Dedicated to the heroes & heroines of the Penang Hospice Society, the doctors, nurses, staff & volunteers.

## The Recognition

With the help & service you provide, you journey with us, the patient & the family alike, through the challenges that coping with cancer entails.

Your availability, your willingness to come, to share & advise reduces the uncertainty and isolation that comes with not knowing what to expect & what to do.

The dedication and compassion you bring in seeing the person behind the illness and not just only a patient comes through in the way you enquire, suggest & affirm,

The gift of hope, the gift of support, the gift of encouragement open doors and empower the helpless to find strength to face the future whatever it may hold.

Tentative so as not to intrude, sensitive and skilled you engage and encourage enduring, enriching memories that comfort.

Truth be told, life & death may lie beyond our power to comprehend but you through your service, faith, friendship, compassion & concern bridge the span, help confront the loss and nurture memories that bring hope and comfort.

What we have found HOSPICE brings

- H** Help & hope
- O** Opportunity to take ownership
- S** Selfless service that reaches out
- P** Personal, professional presence
- I** Invitational, inclusive, involved initiative
- C** Care, concern, compassion
- E** Empathy, engagement, & empowerment

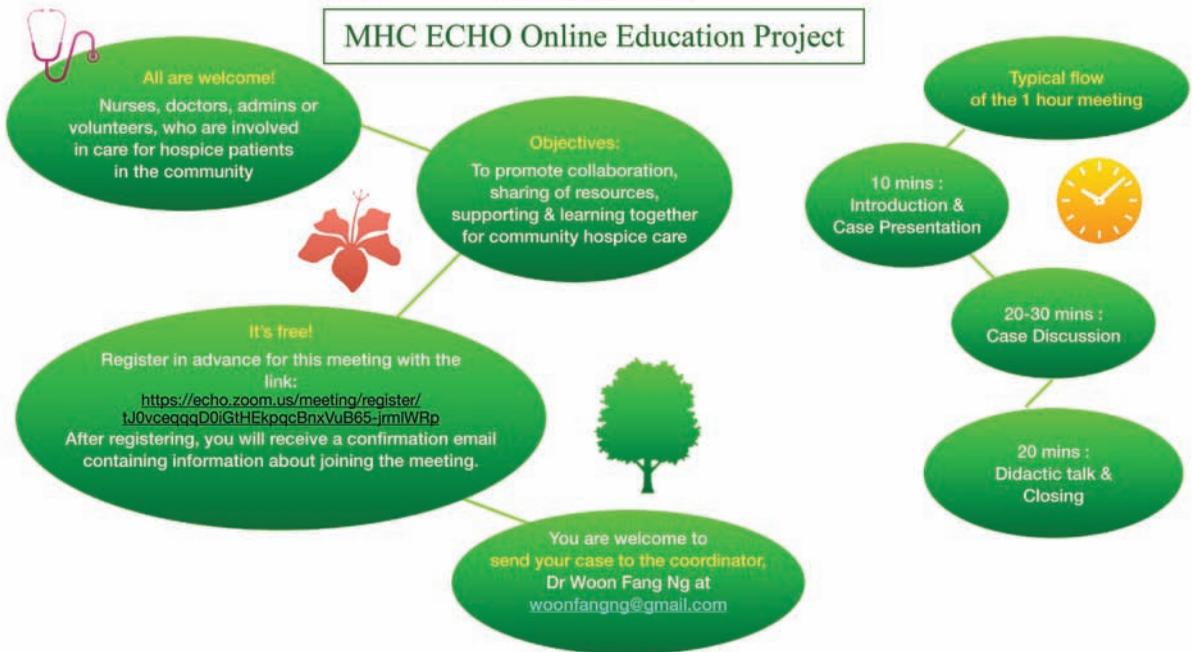
All of which combine to make a meaningful difference.

Thank you

(This article was first published in the 25th anniversary book)



## MHC ECHO Online Education Project



## MHC ECHO upcoming schedule



On alternate Fridays



| Date & Time           | Topic  | Speaker of the Didactic Talk | Facilitator       | Case Presentation           |
|-----------------------|--|------------------------------|-------------------|-----------------------------|
| 19.3.2021<br>9am-10am | Good communication skills                                  | Dr Ng Wan Jun                | Dr Loh Ee Chin    | Hospis Melaka               |
| 2.4.2021<br>9am-10am  | Supporting parents of children with cancer                 | Dr Tan Chai Eng              | Dr Lam Chee Loong | ASSISS Hospice              |
| 16.4.2021<br>9am-10am | Comfort end of life care at home                           | Dr Tay Khok Tjian            | Dr Loh Ee Chin    | Persatuan Hospis N.Seremban |
| 30.4.2021<br>9am-10am | Managing breathlessness at home                            | Dr Carol Lai                 | Dr Ng Woon Fang   | PCAKK                       |
| 21.5.2021             | Occupational therapy for hospice patients in the community | Ong Xie Jin                  | Dr Ng Wan Jun     | Persatuan Hospis Terengganu |

If undelivered, please return to **HOSPICE BULLETIN, Rumah Hospis Pulau Pinang, 250A, Jalan Air Itam, 10460 Penang, Malaysia**  
**WISH LIST**

## **APPEAL**

### **ADOPT PATIENTS TO HELP US PROVIDE PALLIATIVE CARE**

Palliative care aims to reduce health related suffering for people with advanced illnesses.

Penang Hospice Society (PHS), registered in 2001 is a charitable tax-exempt, Non-Government organisation. Our focus is providing Palliative Care for patients with advanced, life threatening illnesses. This includes patients who no longer respond to curative treatment. This care does



its best to improve the quality of life of the patients and their families through the prevention and relief of suffering by means of early identification, assessment and appropriate treatment of pain and other problems – physical, psycho-social and spiritual.

### **THE HOSPICE AT HOME PROGRAMME**

This programme provides Palliative Care by experienced doctors and nurses in the homes of patients with advanced diseases. This innovative service, not provided by the Government Health Service, is provided free of charge. Since starting this service in 1992, we have serviced about 10,000 patients and their families.

## **OUR APPEAL**

The average annual cost for looking after a Hospice patient is only RM1,500. We appeal to you and/or your ORGANISATION to ADOPT one or more patients.

We will provide you permissible information of the patient/s you adopt, and provide you with regular updates.

Change of address       Remove from mailing list      (please tick where appropriate)

Name: \_\_\_\_\_ Tel: \_\_\_\_\_

Address (new): \_\_\_\_\_ Fax: \_\_\_\_\_  
Postcode \_\_\_\_\_

Please send / fax this to:

Rumah Hospis Pulau Pinang, 250A Jalan Air Itam, 10460 Penang, Malaysia.

Tel: 604-228 4140 Fax: 604-226 4676 Email: penanghospicesociety@gmail.com