

HOSPICE Bulletin



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Malaysia
PENANG BRANCH

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

WILL 2023 BE A NEW DAWN?

By Dato' Seri Dr T. Devaraj

The penultimate line in the editorial in January this year was "As 2022 dawns the hope is for a better year. Keep safe. Stay well". Readers will recognise that this was in the year when the country was embarking on the transition of Covid 19 to an endemic stage. Factually it has been largely successful and thankfully new variants have not established themselves in Malaysia thus far. Getting booster doses as advised by the Ministry of Health and sensible personal precautions are still to be observed as integral to an endemic disease.

Many more pressing issues facing the people, the country, our region and the globe have been making headlines with uncertainty fuelling anxiety and despair. Foremost for us has been the call for a stable government. The voters in PRU 15 have decided in ways that has resulted in a hung parliament. Congratulations to all involved in forming a unity government. As civil society we can only hope for a government that will be around for its full term and that will address the felt needs of the people. So our good wishes for the Government.

What about the Penang Hospice Society? The title of the editorial in January 2021 was "Palliative Care in Malaysia – where are we now? For starters 2022 was the thirtieth year of Hospice in Penang. Numbers provided medical care at home have increased over time with a cumulative total of over 11,500 patients by end of 2022. While public support has been forthcoming all these years in recent times we have received more financial support from the Ministry of Health and the State Government.

On 6th October last year there was, for the first time a gathering of hospice providers from the community, medical department, private hospitals and the Pusat Perubatan USM to share views under the topic of "What's next for palliative care in Penang". Currently only about 1000 persons get palliative care in Penang annually. In terms of number of people suffering from cancer and other non-communicable diseases who will need palliative care in Penang annually a study published last year estimated that it was about 6 -9,000 persons. Looking forward to 2030 it would rise to 25,000!

For Malaysia the current need for palliative care is about 130,000 with only about 10,000 being cared for. Are there any prospects for a meaningful change? Who will provide care? The two largest carers at present are hospice NGO's (medical care given in the homes of patients), numbering about 24 at present and very largely urban and the public hospitals with Palliative Care Units. NGO's will never have the resources - material, manpower, money -to make any significant impact. So the task will fall on the Ministry of Health to provide care in hospitals (institutional care) as well as care in the homes of patients. While the latter may be seen as an innovation for the MOH yet, in developed countries that is the norm for decades! In our region Taiwan provides such a service and Thailand has taken some steps too.

An additional and more important reason for MOH to embrace medical care in the homes of patients is changing morbidity trends here and globally – that more and more people are going to live longer and most will have to contend with some health problems or multiple problems especially as they age. Such people will need LONG TERM CARE. Many studies have shown that it needs to be done and can be done with care of quality, greater patient and family satisfaction and financially feasible. It has also been shown that such an approach is more than worthwhile for a number of other reasons – it will reduce the current load on hospitals, there will be seamless care (between institutional care and home care), and the patient and family empowered to care at home along with as needed support from health professionals. Yes, telehealth will have a role but can never replace hands on care.

One resource that the MOH will need in order to embrace long term care in the home is money. What is heartening is that all the three main coalitions which took part in PRU 15 had an increased budget (actually targeting a doubling) for health care in their manifestos. If the election had not been called a white paper on health care reform (including a rise in percentage of public money for health care from the current two percent to 4 percent of the GDP and a novel change to a WELLNESS APPROACH to health from the decades of a SICKNESS APPROACH would have been tabled in Parliament by the outgoing Minister of Health. There has been much public pressure for such a dramatic increase of money for the public sector and there are indications of sufficient support from parliamentarians for such a move. We must thank Covid 19 for bringing about this, for it, not only in Malaysia, but globally showed up the many deficiencies of health care systems.

Will there be a new dawn for health and health care? Yes, I think so. Change is always difficult. Reality is that change usually comes in small increments and time is needed – in today's language it will not be a 5G or whatever faster! The three key players in health and health care – the public, the health professionals and the government – must indeed be the stewards for a better and longer health span for every human being. In recent decades the essential roles of civil society have come to the fore. Malaysia too, though a young democracy, needs to walk this path to human progress for a better world.

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.

Tel: 04-228 4140 Fax: 04-226 4676

Email: penanghospicesociety@gmail.com

EDITORIAL TEAM Dato' Seri Dr T. Devaraj, Tan Sri G.Dhanarajan, Dato' Dr Santhiram Raman, Ms Joon Joon Siew & Mrs Cheng Bolton

PUBLICATION ASSISTANT Ms Chitra Alagan

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.

www.penanghospice.org.my
www.relayforlife.org.my
www.ncsmpenang.org

May this holiday season be bright and the years ahead turn out to be just right. Warmest wishes for good health and happiness from all of us at Penang Hospice Society. Have a blissful new year!



Happy 30th anniversary Penang Hospice Society



30th anniversary of Hospice in Penang

Charity organisation celebrates 30 years of hospice service to society (first printed in *Bulletin Mutiara* – 8 October 2022)

HOSPICE service was made available in Penang some 30 years ago.

It was initiated by the National Cancer Society of Malaysia (Penang branch) in 1992 and was taken over by the Penang Hospice Society in 2010.

Penang Hospice Society maintained the free hospice service all these years.

Chief Minister Chow Kon Yeow, who was present to witness the important occasion, commended Penang Hospice Society for its continuous service to the needy community.

“We thank the National Cancer Society of Malaysia (Penang branch) for initiating this service in 1992 and the Penang Hospice Society for taking over this program in 2010 and maintaining it as a free service all these years.

“I am happy to note that the ‘Hospice at Home Program’ has become a model for the country.

“Today’s celebration is about recognising the work that Penang Hospice Society has been doing, in addition to increasing the awareness of the public that medical care is available in the homes of those who are suffering from advanced illnesses in Penang.

“This programme is aimed at easing the suffering of patients and improving their quality of life. At the same time, families are empowered to care more about their loved ones at home.

“The ‘Hospice at Home Program’ illustrates the value of care in the homes of the patients to complement the care given at hospitals thus promoting seamless care.

“The importance of care in homes as part of community care is being advocated globally.

“Health delivery has to be integrated with community care because of the increase in non-communicable diseases (NCDs) and ageing. The increase has resulted in a rapidly growing need for long-term care,” Chow said in his speech at Penang Hospice Society in Jalan Air Itam today.

Chow said that families could take on such care but they would need both health and social services to go to their homes.

“Such practices are already available in many developed countries. Any move in this direction will be towards fulfilling one of the visions we have for our state and country – a caring society,” he added.

He also thanked and congratulated the volunteers and staff who have contributed to the selfless community service.

“I would also like to thank the people who have provided encouragement and financial support to assist the needy,” he said.

Also present were Penang Hospice Society chairman Datuk Seri Dr T. Devaraj and Vice-chairman Datuk Dr Chan Kok Ewe.



The guests celebrating the significant milestone at Penang Hospice Society.



Chow delivering his speech.

World Hospice and Palliative Care Day 2022

World Hospice and Palliative Care Day 2022 was celebrated at Rembau Hospital, Negeri Sembilan with the theme "Healing Hearts and Communities". The focus of the celebration was on the aspect of recovery and emotional support for family members and the community when dealing with patients and during the phase after the loss of a loved one. The staff of Penang Hospice Society participated in the event. The then Minister of Health, Khairy Jamaluddin officiated the celebration.



Relay For Life

JUST RAMBLING AGAIN

By Mui Siew Koon, a cancer survivor and passionate supporter of cancer and hospice activities.

The last 3 years have been very challenging for everyone in the world, only in different degrees. Covid-19 has disrupted the lives and livelihood of millions. Families have been separated. Businesses have closed, some temporarily, some permanently. Schools, colleges and universities could not function. The always changing standard operating procedures have caused a great deal of confusion. At least our government takes the necessary measures unlike many countries where citizens are left to do what they themselves think right, causing more chaos and more pain.



On a personal note, the last 3 years have been a very challenging time for me too. The post-surgery period after my valve replacement operation and bypass surgery was horrific. The 3-weeks in and out of the intensive care unit / critical care unit / ward was full of physical as well as mental agony. I nearly died a few times with my husband being summoned to the hospital in the wee hours of the morning. Fortunately each time the cardiac team managed to resuscitate me.

Hallucinations of gruesome scenes with terrifying noise whenever I tried to sleep were frightening. Finding a comfortable sleeping position was not easy at all. The sensation of being hot could not be solved as the temperature in the hospital was centrally controlled. When I was cold, the nurses just piled blanket upon blanket on me.

This hot and cold sensation continued even at home. Then the problem was easily solved with my air-conditioner remote control and my hairdryer in my hand. I was told that after having had my body temperature lowered drastically during the operations to minimize blood loss, it would take time for my body to readjust to normal.

During the 3 weeks in the hospital, I had fluid drained from my chest cavity in the ward once and another time in the operating theatre under general anaesthesia. The forced daily physiotherapy sessions were hell too.

During the first 3 months after my discharge from the hospital, I was very helpless and frail. I could hardly walk or talk. I was easily tired and sleepy. I was usually in bed or on the sofa. Food was tasteless. I could not stand the sight of hard-boiled eggs and ice-cream for months as I have had enough of these whilst in the hospital. I had these for breakfast, lunch and dinner then.

I am very grateful to have had my heart problems attended to in a private hospital, burning a big hole in my pocket. If I had waited in line at the government hospital, the surgery would have been postponed indefinitely as the given date was late March 2020. By then it was a complete lock-down. I am indeed very grateful to have been attended to by an excellent thoracic-cardiac team. Together with excellent love, care and support from my family and help from friends life has returned to almost normal. Breathlessness is now very much less although I still cannot walk far or fast.

In the last 2 years, I have struggled to learn a lot, to keep up with the current digital world but I still have a long way to go. I am using my cell phone and computer more, to get things done, such as ordering food and groceries, paying bills, transferring funds, taking part in zoom and WhatsApp meetings. The Penang Floral Art Society of which I have been the president for decades, had successfully held its annual general meetings the last 2 years via WhatsApp.

Many of my friends consider me a very brave person, brave enough to serve as the principal in a rural secondary residential school, on the fringe of the Jengka Triangle in Pahang, some 6-hour drive from home, travelling to and fro on my own, even in the storm.

Many think I have been very brave to join an all-men committee in the NCSM, Pg Branch since 1978 and remained as the only lady there for more than 2 decades before other ladies joined in and to openly acknowledge my radical mastectomy journey and to be the sole volunteer in the Reach to Recovery programme, offering a listening ear to some hundreds of newly diagnosed breast cancer patients, giving messages of encouragement in public and in writing.

With variants of Covid-19 lurking around, I am indeed very scared. I put off visiting my dentist for 2 full years to get my chipped molars fixed. Similarly I delayed having my eyes tested. I have not ventured out to have my hair dyed. With my platinum blonde look, I am often mistaken as my husband's mother. Ha! Ha!

Incidentally I finally gathered enough courage to read the report of my 5-hour heart surgery. The intricate details really scared me as it was such a delicate procedure. I wish I had not read it.

Though S.O.P. is more relaxed now, I still very prefer to wear my mask, once I am outside of my home, keeping a distance from others and avoiding crowds. I have not ventured to dine-in except in airy, open, non-crowded eateries. I still depend on take-away food from familiar and less crowded shops.

I have only attended certain functions especially those related to cancer and hospice care, my favourite NGOs.

On March 18, as vice-president of the Penang Breast Care Society, the only registered cancer support group in Penang, I accompanied our president together with another 2 key committee members, paid a courtesy call on Toh Puan Khadijah Mohd Nor, the wife of our new Governor.



On 8 October I was present at the 30th anniversary celebration of hospice care by the Penang Hospice Society, where I was an active committee member for a very long time.



Recently I served again as the chairman for cancer survivors, for the 16th time, in Relay for Life Penang 2022. This event was held after an absence of 2 years, on 4 December. Despite the short notice given to us by our headquarters NCSM KL, response was good, in terms of participation and donations collected.

I am very grateful to have great friends, who not only gave support by signing up and taking part in the walk, giving donations without being asked, manning the counters, etc. Sincere thanks need to be recorded to Practical Printers for giving us the recyclable bags, calendars, note pads for the survivors and for printing our certificates, as well as for all the free and excellent services given to both societies all these years. Many thanks too to Among Friends for providing the cake again this year.



Our society is indeed very grateful to have wonderful supporters, putting up stalls, providing food, games, fun, music and merriment.

I was greatly surprised again to have been the participant with the highest donation collected as well as being the leader of the team with the highest collection. I only had 4 members in my team this year, not 10 as in the past, the reason being many of my close friends had donated to our building funds earlier in the year.

The year-end monsoon is affecting Malaysia very seriously. Torrential rain has caused flooding in many parts of the peninsula as well as in Sabah and Sarawak. Thousands of people have to be evacuated. The loss of homes, lives, property is tremendous. In the last 10 days alone, the landslide in Batang Kali took away the lives of 31 and injured 61 both children and adults.

I am very grateful to have survived till now. I am very blessed that I am better off than many people in Malaysia, and in the world.

I can face dangers that I know, not the invisible type like Covid-19 variants. I am very much aware that I am at high risk because of my age and underlying medical issues. Thus I take care and stay safe, following S.O.P. faithfully. I give thanks to God all the time for his blessings and try to do good in return, helping the less fortunate.

Novemberjazz 2022

Novemberjazz 2022, an annual charity dinner show of the society was successfully held on 10th of November at the E&O Hotel after a 2 year hiatus due to Covid. The society is grateful and thanks all of its donors and sponsors who helped raise RM98,000 through this event.



Donors

Ms Jasmin Khor, the founder and managing director of Jammin Sensation, a prominent music school in Penang has always been a constant donor and supporter of the society. The school held its' 13th annual concert themed "Variety" at the Dewan Sri Pinang on 15 December 2022. The concert presented various genre of music: pop, rock, jazz, latin, R&B, anime, classical, oldies and Disney. Ms Jasmin, students and supporting artists helped raise RM10,000 through ticket sales and sponsorship to Penang Hospice Society Hospice.



Kompleks Bukit Jambul Ratu Kebaya International 2022



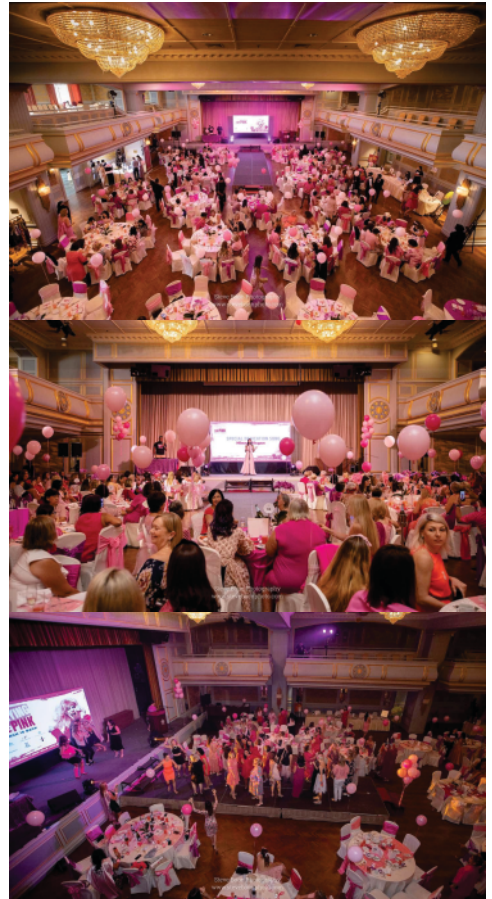
The event was organised by the Kompleks Bukit Jambul (JMB) for the 13th time and took place at the Setia SPICE Arena in Jalan Tun Dr Awang, Penang. Proceeds from the event's ticket sales were donated to charities as part of its corporate social responsibility programme for 2022. Penang Hospice Society was one of the 3 NGOs to receive RM10,000 each.

Pink Ladies Brunch, 7 October 2022

After a one year hiatus, there was an overwhelming show of support for the brunch's 14th edition themed "Slaying the Pink" which was held at the E&O Hotel on 7th of October in conjunction of breast cancer month. The hall was filled with beautiful women who mostly came adorned in pink.

The event organisers Ms Jennifer Sheppard, Ms Tiina Luckins and Ms Susie Macmillan along with the committee hoped to raise at least RM125,000 from the brunch as well as from several other ongoing activities throughout October and November. The amount will be donated to Mount Miriam Cancer Hospital and Penang Hospice Society.

"The funds raised will not only help cancer patients but also help their family members."



Lim's Grand courtyard

Script written by Lim Chai Lin and Director by Lim Chai Lin.

The Lims, 1950. A respectable local family. An old woman (Chen Feng Yi), who is the mistress of the house and has two sons, the eldest son (Lim Shi Jie) and the second son (Lim Shi Jun).

When the husband of the old woman passed away, he left a suicide note that stated where all the rights and property are left to the elder son, Shi Jie. From that onwards, Shi Jie became the head of the family. In this era of male superiority and female inferiority, women are necessary and have to obey their husbands' orders, as well as help their husbands to teach their children. Because of the feudal society, the ugly side, power struggle, strong and domineering, all kinds of darkneses is also emerged in this home. Of course the kind-hearted and the loving also appeared in the house.

Shi Jie, a stable and amorous man, has four wives, the first wife (Xu Su Yin). She is a housekeeper, who seldom smiled at home and was serious in her speech and manner. She always puts effort into the family, tolerating her husband's three wives and four concubines. She is such a woman, silently suffering, a woman destined to share a man's heart with others.

However, Su Yin has a son (Lim Jian Wu), who is the family's precious son.

The second wife, Lee Yan Rong, was often overbearing, strong and unforgiving. All wives have to be respectful to her, otherwise she will torture and bully them. The third wife, Yuan Yu Chu and the fourth wife, Gao Mei Shan, both came from a small family. Both of them met Shi Jie in a dinner party and in the arrangement of the old woman, they then got married into the Lims. This is for the purpose of inheritance.

The following is the fifth wife of Shi Jie....

To put up this show, we've been preparing for it from the beginning of the year 2019 until 2020 . We feel very glad that all this while donors and sponsors are always supporting us. The cast and students together are working hard on the practise and rehearsal to bring the best on stage for performance.

Unfortunately, we have to stop the whole project when COVID-19 hit the whole world.

We had no choice and totally stopped the project for almost 2 years. When it comes to 2021 we started our practice again online via ZOOM , and also we practised face to face when the Government lifted the movement control restrictions. Although we were having a hard time in COVID period, we still carried on our practice as much as we can.

In 2022, we eventually were able to work it out and practice face to face more and all the cast and students stayed on together to make this show happen. Therefore we fixed a date 22-10-2022 to bring the show up at Dewan Sri Pinang. Again we are thankful that some donors or even the same donors and sponsors were still supporting us for this project that made us able to donate an amount of RM40,000 to Penang Hospice Society.



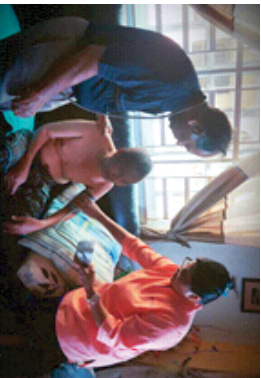
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WISH LIST

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.

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