



HOSPICE Bulletin



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

Celebrating 30 years of Hospice in Penang (1992-2022)

By Dato' Seri Dr T Devaraj

Yes, hospice has been a part of the Penang scene since March 1992. This community service was innovative for Malaysia and has developed into a niche service of medical care in the homes of patients that has become a model for the country. As a charity the going has been tough all these years but the silver lining in this mission to minister to suffering arising from illness has been the public whose understanding and generosity has sustained the Hospice at Home Programme (HHP). In recent years more financial support for the programme has come from the Ministry of Health and the Penang State Government for which we are grateful.



A tribute is due to the volunteers and staff who have borne the torch over the years. This has come to a greater prominence with Covid as this team continue to be servicing as front liners. All the eight nurses have been covid contacts, some more than once, and two had covid and recovered. A big thank you to the many doctors in Penang, especially the palliative care physicians for their help in looking after patients in our programme.

Of some interest would be three significant developments, one that the Hospice at Home Programme was given a licence under the Private Healthcare Facilities and Services Act 1988 last year. This year an Electronic Management System has begun which means that manual documentation of patient care has ceased. In terms of staff a Nurse Manager has been appointed this year to monitor and strengthen the service.

Many proposals have been suggested for the 30th year celebrations. One in particular is a garden party to say thank you to the many volunteers and staff who have contributed to HHP and the Penang Hospice Society. It will be at our office – Rumah Hospice Pulau Pinang in the latter part of this year.

What of the future? In terms of infrastructure we will begin construction of our building, the Hospice Centre this year. We have some funds but will need more and look forward to the generosity of the public to bring to conclusion a dream that really began in 1996. In terms of HHP itself we do hope to appoint a full time doctor as staff. Another aim is to continuously enhance the quality of care that we provide in the homes of patients, leverage on telehealth and continue to empower the patient and family towards good compassionate care.

“THANKS, TERIMA KASIH, NANDRI, XIEXIE”

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HAPPENINGS:

• CARERS' MEETINGS_Penang Island

Day : Every Thursday via zoom
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

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

Sharing

By Dato' Krisna Dass – Volunteer doctor with Penang Hospice Society

8 years ago, Dato' Seri Dr T Devaraj was looking for a doctor to attend to palliative cases in Seberang Perai. I readily volunteered to serve this worthy cause.

It had been very interesting but there are also painful moments as I visited these unfortunate people. Interesting in the sense that, I was able to see many places in the mainland especially the kampongs with beautiful gardens, fruit trees and friendly people. It was more or less a weekly outing for me as I was unable to travel overseas in the last 3 years. The nurses Esther, Wey, Linda and Gan (unfortunately I was not able to visit with Anne Raphael as it us too far for me) have become expert drivers and familiar to these "hidden" places one would never visit. We are lucky to have these dedicated and experienced nurses who spend many hours driving from one place to another to see the cases. In spite of the stress they are all friendly and show a lot of compassion towards the patients. The families and the patients always look forward to our visits, more so when they see a doctor consoling, advising and recommending treatment to other ailments like respiratory and gastric problems and anaemia etc.



There were two unforgettable incidences. A terminally ill with pancreatic cancer patient was admitted in a nursing home. I heard about his birthday and so bought a cake for him. He was literally in tears as he never had any celebration all his life. That was his first and last birthday function among other inmates. He passed away a week later. Another was a 41 year old lady with cancer of the vulva in excruciating pain. In spite of all the medications, she was groaning in pain. Her husband admitted her for sedation which helped to control the pain and led to a more peaceful death.

I just have to say that this noble service to relieve the suffering of the terminally ill patients has given me so much of personal satisfaction. I am also truly inspired by the pioneering and dedicated service of Dato' Seri Dr Devaraj to Penang Hospice Society.



"You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die." ~ Dame Ceily Saunders

A Light in the Darkness

By Gong Wooi Khoon

"We are very sorry to tell you that we have done all we can for your loved one. Perhaps you may want to take him home so that he can spend his last days in the comfort of home, surrounded by family and friends?" the sympathetic doctor in the surgery ward of the Penang GH said gently. Whilst we had been aware for a few days that Jin had been on the decline despite the best efforts of the doctors from the SOPD, Urology, Oncology, and Palliative departments, it was still a shock to hear our fears verbalised.

Fortunately, we had established contact with the Penang Hospice Society to arrange for their help in this difficult time. The nurse assigned to us, Nurse Molly, called us soon after to go over our plans. Thanks to a great deal of help from Dato' Seri Dr. Devaraj and Ms. Chitra, the Hospice was gracious enough to provide us with a hospital bed and a wheelchair so that we could get the house set up to be able to bring Jin home the same day. He was delighted to be home in a familiar environment where he could be around family.

Nurse Molly came to the house to visit within a day or two and after getting all the necessary medical details, she spent some time going over the best ways of making Jin comfortable, from bigger things down to minor details which made a lot of difference (like where to put an extra pillow or two for Jin to feel more comfortable). She also spent some time getting to know him and the rest of the family better in a completely unobtrusive way. Nurse Molly extended us a "lifeline" in that we could phone her anytime 24/7 and she would try to help over the phone, suggest what we should do, or even come to the house outside of office hours in case of an emergency.

Over the next two weeks, Nurse Molly was constantly in touch with us over the phone as well as visiting every few days. She went over the best ways to give medicines, passed on advice from specialist doctor volunteers with the Hospice whenever needed, and also discussed important issues such as possible tube-feeding and resuscitation with us in a sensitive way. Nurse Molly always cheered Jin up as they kidded each other frequently. For example, he once shook his finger at her saying, with a grin "You are very sneaky, talking behind my back". Nurse Molly laughed and promptly replied "You are very sneaky too, eavesdropping when we thought you were sleeping!"

Towards the last days (Nurse Molly is so experienced that she could see this coming), she started to prepare the family for the end, talking to us gently about what signs would herald the coming-to-the-end-of-life and also walking us through the important formalities that would need to be done in the event of death. The Hospice also lent us an oxygen concentrator to help Jin with his breathing. This was a great comfort in his last few days.

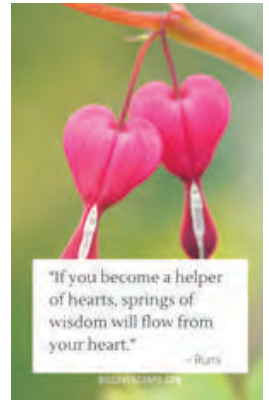
Losing a loved one is a terrible experience, but the Hospice helps cushion the blow by providing important resources as well as skilled and sympathetic support for patients as well as their loved ones during the last days, and even into bereavement. Jin's family and I would like to take this opportunity to say a big "Thank You" to the Penang Hospice Society for their fantastic "Hospice at Home Programme" – you really are "A Light in the Darkness".

Hospice at its best ... reaching out to the community

By Ms Zakiah bt Abul Khassim

It is indeed an honour to be associated with an organisation that provides such a priceless service to the community. It has always been my dream ever since, to have the resources to provide such services to the community one day. Hospice had inspired me indeed as to what extent one can give back to the society.

Abundance of gratitude to Dato' Seri Dr T. Devaraj, who pioneered the Hospice at Home Programme in 1992, a charitable non-governmental organization which provides holistic medical care in the homes of patients with advanced life limiting diseases, mainly cancer along with non-cancer patients. Hospice is successfully providing such services with love, humility, compassion and respect by enhancing and preserving the dignity of all beings right through to the end of life. Indeed that was what we experienced till the last breath of my late mom. I have seen and experienced being able to provide the best care for my late mom with the best support right through the end of her life with the help of Hospice.



Hospice as I know, has a multi-disciplinary team of dedicated nurses, specialised doctors and lay volunteers who visit the patient at his/her home to address the problems of the patients and look into their physical issues such as pain, psycho-social, as well as their spiritual needs with the aim of reducing suffering while at the same time helping the family cope by providing emotional & practical support. It would have been a difficult experience for us if not for the support that we have received from Hospice.

The service Hospice had provided is more than just providing medical equipment such as hospital beds, suction machines etc but also providing guidance to family members. I personally have learnt many new things on palliative care. I first came to know Hospice when I visited the home to see my client as practicing lawyer. It was her last few days and I was there to get instructions from her to write her will. The services provided and the environment immediately caught my attention as it was full of warmth and seeing my client who was terminally ill placed in the most comfortable manner possible touched my heart. I couldn't forget the experience although it was a long time ago.

Then in 2007, I saw how Hospice had provided its personal and loving touch on a distant relative of mine till her last breath. Some time later, my auntie was terminally ill and again I experienced Hospice tender loving care for my auntie for 9 months. Nurse Molly, a palliative care nurse with Hospice had provided her best assistance and advice. Words would not suffice to describe our gratitude to her. Hospice had given us more than we could ever expect until my auntie's last breath in 2017.

Shortly after, my dearest mom was down with a brain stroke and in a comatose condition for two and a half years. Hospice was a great help and support not only to my mom but to us. We were taught tirelessly on how to handle a bed ridden patient, from doing suction, to cleaning up and also dressing wounds in a non-sterile environment. Nurse Molly took the time to patiently teach us and she was ready available in emergency situations even outside her working hours.

Indeed Hospice service has been incomparable with dedicated staff and doctors. As at yesterday, Hospice had again extended its wonderful service to my auntie Zainab Binti Abdul Razak who had fallen ill and became bed ridden due to old age. She was sent home and Hospice had immediately supplied her with a hospital bed and the necessary equipment which is convenient for her comfort and safety. The nurses also came in to help the family to adjust with the new situations and provide them with the much needed advice. Again there are no words of thanks that would suffice to Hospice especially in situations like this where family members are anxious and worried.

I am truly inspired with the services that Hospice had provided for. It makes me wonder with the question Martin Luther King, Jr asked, "Life's most persistent and urgent question is, what are you doing for others?"

I would like to end this short moment with the biggest applause to Hospice for its yeoman services it is extending to the community. Special thanks to Nurse Molly, all the nurses, doctors and volunteers. Only God can repay all your kindness and assistance. Your work is incomparable. Keep it up and be the best always.

"At the end of the day it's not about what you have or even what you've accomplished... it's about who you've lifted up, who you've made better. It's about what you've given back." –Denzel Washington

REFLECTIONS ON HOSPICE REFERRALS

By Dato' Seri Dr T. Devaraj

The Hospice at Home Programme (HHP) has welcomed referrals for care at home since its inception in March 1992. The only conditions were that the ill person must be residing in Penang and has a family carer at home. Apart from citizens we have had foreigners and refugees too. Many clinical issues surfaced as patients sought the service such as who was eligible (with what illness) when to refer, and who can refer amongst others. At the beginning focus was on advanced cancer patients often labelled as "terminally ill". Over time this label was dropped to "a person with advanced illness".

Another change was admission of non - cancer patients with numbers growing yearly. By 2021 it's proportion had risen to 18%. In developed countries this is nearer 30%. Does this match the coverage needed? The answer is no. Simply because cancer as a cause of advanced illnesses is already dwarfed by other non- communicable illnesses namely cardio-vascular, respiratory, neurological including dementias, renal and other organ failures. Besides there are children with serious congenital or birth defects. Taking in more non-cancer patients poses many clinical challenges to our nurses and doctors and for the management, a pressure for more resources.

On who can refer the policy was open, meaning a doctor or a family member. From the former, apart from demographic particulars, more clinical information was expected. A referral form was made available and a few years ago the three hospice services in Penang (two providing home care, one only in patient care) decided to have a common referral form for the use of doctors.

For family referrals – the family was supplied with a referral form. Over time sources of referrals have changed - from family to doctors. An analysis of referrals from 2017 – 2021 shows referrals from doctors, both from hospitals/ and Palliative Care Units (PCU) were 88% and family 10%. It will be pertinent to note that in Malaysia some hospice services admit only if referred by a doctor while some only accept cancer patients.

A feature common to all hospice services in the country is late referrals which is a perennial issue. An analysis of the period under care in HHP until death (2017-2021) showed that of the 1819 deaths:

Period – days	deaths %
0-10	30
11-30	27
31-90	29
>90	14

Many of the deaths occurred on the day of referral or a day or two later. This is shocking especially because in Penang the service started 30 years ago - that long suffering patients were not addressed through a community service. Other home care programmes in the country face similar issues. That this is not a Malaysian problem as can be seen in an article in the New England Journal of Medicine (Gail Gazelle 2007) where one third of patients referred for hospice care lived for only a week. One reason mentioned in this study, about the reluctance of a patient and family to accept hospice care in the United States (which was funded by the state) was that a treatment like parenteral nutrition would not be provided. Another was that many services were small where care provided by nurses and doctors were seldom available.

While there is more awareness of hospice care in the country (medical profession and the public) a moot question is why has this not translated to earlier recognition, treatment and referrals? Some problems of the public - avoid conversations on bad news; may be unaware or not told of how ill a patient is by the doctor, may feel that hospice means giving up when still hoping for a cure or just control of the illness for some time. Thus the public may see hospice as a "jalan mati". Some doctors do say "nothing can be done" and discharge the patient – often a communication problem here for what the doctor was saying was that the disease was so advanced and thus no further treatment of the disease was possible. It would have helped if at the same time the doctor assured the patient and family that any symptoms will be treated and or the patient will be referred for hospice care, in the hospital or a home service.

Much has been written about physician's attitude to dying and death. I was shocked when in medical school the Professor of surgery, while talking of the important role of a doctor to save lives he went on to say but not do so officiously. I sought advice of a senior doctor who said "in time your experience as a doctor will help you understand what the professor meant". Some reasons attributed to doctors are – death of a patient seen as a failure; referral to hospice means dashing the patient's hope; unsure, not comfortable conveying bad news; that the time has not come for referral (doctor's often over estimate how long the patient has); that hospices are for the dying and hence do not help people live. Other factors are time is needed for good communication as well as privacy. The NEJM article also stated that oncologists only look for response of the tumour to treatment and not on symptom improvement or quality of life. In this respect doctors in hospitals have a curative mind set and not open to a palliative mind set. The reality is that the palliative approach can provide better outcomes for the patient, carers at the end of life and often at lower costs. A factor which is seldom mentioned is the push (by patient or family) and the pull (by the doctor and the hospital) for continuing treatment giving rise to even the question of over – medicalisation of death or futile treatment (Scott Murray and Jordi Ambias 2021). The Lancet Commission on the Value of Death (2022) alludes to this as happening in developed countries but I feel that it is already happening here. Some in the public may even say it is their money and their right of choice. Perhaps underlying all this is a perception by some doctors and the public that science has all the answers. Science has some answers, not all and the covid-19 pandemic illustrates this. What is true is that the advances in medical knowledge and technology will increase ethical dilemmas at the bedside - a treatment can be done, ought it be done is the question! Who decides? Who pays? Who deals with the consequences in terms of care? Many other questions arise and all (family, doctors, carers) and societies will have to make really difficult decisions.

What are the solutions? Negative thinking about hospice care by the public will perhaps take a while to recede. For doctors training in communication and exposure to palliative care at undergraduate level should be a norm. I was surprised by this statement by Dr Ros Taylor, a palliative care consultant "Many medical school curricula still have just one day in 5 years focussing on palliative care issues, often with no placements in a hospice or palliative care team." (Udani Samarasekara, 2022) She is further quoted as saying "I believe that palliative medicine is just good family medicine with more time". In comparison the Penang Medical College has a tutorial and a days' placement in HHP. Some medical schools in the Klang valley do more teaching, including students in master's programmes. The following quotes by the French philosopher and the American philosopher who was co - founder of the Hastings Center respectively, are worth reflection:

“Neither the sun nor death can be looked at closely” - La Rochefoucauld (1613 - 1680)

“If as physicians we believe that advances in medical technology can indefinitely postpone death then it is a delusion” - Daniel Callahan (1993 - 2019)



Footnote:

Data is available for place of death of patients in HHP. For many years about 80% occurred in the home which was the choice of the patient and family. We have a rule of thumb - that if a patient (who had been in the programme for some weeks or more) died at any other place than his home it was to be viewed as a failure of care by the service. With time change has occurred as figures for 2017 – 2021 reveal. Of 1819 deaths place of death was 68.5% (home), 18% (hospital), 10% (PCU), 3% (nursing home), 0.5% (others). Studies need to be done to understand this trend and how it ought to be addressed by all the stakeholders.

A perennial problem with referrals often is inadequate information. The form is user friendly – just one page, asking for patient demographics, basic clinical information, results of investigations and awareness of patient/family of the seriousness of the illness. Information from family is often sparse. In-care at home information from the doctor is vital as it helps in clinical management. In home care reliance is on clinical acumen and resort to investigations occurs rarely. I must say that some doctors provide adequate information and a few type – what a joy the latter is as doctor's handwriting is often a scribble, which I must confess I am guilty of it too. One solution is the adoption of an electronic data system (health card) that then is accessible wherever a patient is seen. This was mooted by MOH about three decades ago! Some public hospitals have become paperless while some other hospitals have adopted for some data only. Taiwan adopted this system over a decade ago. For HHP an electronic data system was started this year. All clinical staff and management find it useful compared a manual recording.

Some other features in relations to referrals are – doctors are informed of acceptance, discharge or the death of their patients. Referrals can be in print, e mail, fax, what's App. (penanghospice society@gmail.com; fax: 04 2264676; referral form available at <http://penanghospice society.org.my>)

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Report of the Lancet Commission on the Value of Death: bringing death back into life. Lancet Jan 31, 2022

Getting to know what is Hospice Care

By a grateful husband

My wife is a stage 4 lung cancer patient. She received treatment from Penang General Hospital Oncology Department since the beginning of 2021. On the 18th. March 2022, a doctor from the Penang General Hospital Oncology Department told me that my wife would be placed under the Palliative Care Unit as a measure to provide her with better quality of life and better pain management.

I was quite apprehensive at first. Is the Oncology Unit stopping treatment and giving up on my wife? But after hearing the doctor's explanation that providing my wife with better quality of life and reduces her pain is better than prolonging her suffering, I came to terms with reality. I was told that Penang Hospice Society would get in touch with me and to assess how and what type of services could be provided for my wife.

On 22nd March; a palliative care nurse, Ms.Wey Ah Ee from Penang Ho spice Society paid my wife a visit. Her visit was much welcomed as I have many queries on how I can be a better and more efficient caregiver to my wife. Ms.Wey explained and even demonstrated to me the proper way to turn my bedridden wife regularly to prevent bed sore. She even supplied some pills to help my wife defecate and something for her bed sore. Overall, I have learnt quite a lot from her from that one visit. I was told that she would make weekly visits to monitor my wife's condition.

On Nurse Wey's third visit recently, she brought along Dato' Dr.Krishna Dass who is a Volunteer Physician with Penang Hospice Society. Dato' Dr. Dass examined my wife and spoke briefly to her. I find Dato' Dr.Krishna Dass to be a compassionate, kind and jovial fellow. Having a chat with Dato' certainly brought comfort and eased some stress in me.

Lastly, I would like to thank both Dato' and Nurse Wey for their selfless services in Penang Hospice Society. May God bless you two with happiness and good health.



She is Gone - David Harkins

You can shed tears that she is gone
or you can smile because she has lived.
You can close your eyes and pray that she'll come back
or you can open your eyes and see all she's left.
Your heart can be empty because you can't see her
or you can be full of the love you shared.
You can turn your back on tomorrow and live yesterday
or you can be happy for tomorrow because of yesterday.
You can remember her and only that she's gone
or you can cherish her memory and let it live on.
You can cry and close your mind,
be empty and turn your back
or you can do what she'd want:
smile, open your eyes, love and go on.

Hospice Care

Although the thought of Hospice Care may still be enigmatic for many people, this has not dampened the commitment and effort of the Penang Hospice Society to support families and individuals facing challenging circumstances coping with the practical and emotional demands that come with being a cancer patient or a caregiver.

I have seen first-hand the support and assistance they have provided from equipment such as hospital beds, ripple mattresses, wheel chairs and other articles needed to improve the quality of life and relieve discomfort.

The team of doctors and nurses who visit and guide the patient and care givers navigate the myriad uncertainties, offer dignity and compassion with the message that no one needs to suffer alone and in pain because of a lack of awareness or assistance..

Palliative care, hospice care does not mean hopeless care or caring without hope. Through the tireless efforts of the pioneers, staff & volunteers, Penang Hospice Society has forged an enduring message that in life or death, people matter and that they care.

I join many others in applauding their untiring commitment and appreciating their tireless efforts .

However, they too need our support . Networks make a difference and extend the reach of assistance, In supporting the work of the Penang Hospice Society, we can help in furthering the support offered in the Hospice at Home Programme to others in the community.

See the possibilities

Consider the ripples

Congratulations to the Penang Hospice Society on the 30th Anniversary of the Hospice at Home Programme

Margarita Malayapillay



Afterglow - Helen Lowrie Marshall

I'd like the memory of me to be a happy one.

I'd like to leave an afterglow of smiles when life is done.

I'd like to leave an echo whispering softly down the ways,

Of happy times and laughing times and bright and sunny days.

I'd like the tears of those who grieve, to dry before the sun;

Of happy memories that I leave when life is done.

Hospice Care

By Madam Lucy Goh

Three years ago in the year 2019, when my Mum In law was first diagnosed with CKD (Chronic Kidney Disease) she was put under the care of Hospice-Home-Programme when we made the decision of not letting her go through dialysis for her kidney failure due to her age. She was bedridden and had dementia too.

Being the only care giver and inexperienced, it was tough on me. I would easily be drained out, physically and emotionally which made me tense or feel frustrated easily and at times emotionally down.

Thank God, with the aid given by Hospice Nurse Linda, through regular visits or via telephone conversation and at times she brought doctors along too during some of the visits, I was able to cope well and felt at ease.

Words of advice, comfort, encouragement, moral support, a listening ear are vital for a care giver to be uplifted.

From the frequent visits of the medical staff I was able to pick up some practical techniques which are essential when handling bedridden patients especially cleaning which I realize not so difficult.

This kind of concrete acts of love, compassion and patience shown by the Nurses of Hospice; and rendering voluntary service is a strong message that love knows no boundaries, regardless of different race or religious background.

This small contribution is my way of showing gratitude and appreciation for the dedication and support rendered by Hospice for my late Mum In Law.



My Journey

By Puan Azalina – MAKNA volunteer

GOD'S PLAN WORKS BEST

WHO ARE WE TO QUESTION?

SEPT 2007... RAMADHAN... 15 RAMADHANS TO BE EXACT, ALREADY GOING THROUGH HORMONAL BLEEDING PROBLEMS ... ON TREATMENT.. SETTLED MY PROBLEM OR SO I THOUGHT....

The discovery of a lump in the right breast after "iftar" or breaking fast did not panic me as I had an appointment with my gynaecologist the following Monday. I went for the appointment and the tests confirmed my guess, the abnormal lump was confirmed by mammogram and covered the whole breast like a cauliflower.

I was referred to SOPD Taiping and did my mastectomy on the third day of Shawal. I completed all the chemotherapy and radiotherapy sessions on time.

WHY?

Because my plan was too stressful. God's plan was to give me an extended family even though at the time I was already involved with my orphans and 2 elderly people. Uncle Boy broke into tears when I told him I had cancer. He was so worried that there won't be anyone to look after him. God Rest his Soul. Gone at 80+ before me.

Who says CANCER KILLS YOU

I am living proof that with proper treatment and positive thinking, life can be lived to the fullest. WIRAS AND NON WIRAS NEED A LOT OF HELP OUT THERE. A BIG THANK YOU to my children and family and all the doctors out there who are ever ready to assist whenever help is needed. The list of names is too long to be mentioned.

May God give me the health to carry on with what is needed to be done.



“Happy 30th Anniversary, Penang Hospice Society!”

By Teh Eng Chin

Overall, the global outlook has changed in the last 3 years when COVID-19 (Coronavirus Disease 2019) was discovered in December 2019 in Wuhan, China. It is very contagious and has quickly spread around the world. The COVID-19 pandemic has led to a dramatic loss of human life worldwide and it has presented an unprecedented challenge to public health, food systems and the world of work. Everyone is living in anxiety and fear as COVID-19 virus is like an invisible killer that can end our life anytime and anywhere without us knowing it.

However, I really appreciate the Penang Hospice Society Nurses as they continue their caring job by visiting the homes of cancer patients without hesitation against all odds. The health of cancer patients have always been their top priority. I can understand that they need to overcome a lot of challenges and obstacles during the COVID-19 pandemic period.

I have been under Penang Hospice Society's “Home-at-Home Programme” for almost 10 years after I was discharged from Hospital Pulau Pinang in 2011. During this period I have managed to meet many Hospice nurses. It has provided me a sense of security and joy when dealing with Hospice nurses, as we can share experiences, knowledge on wound treatment, life stories of other people in similar situations.

I am glad that I can have a chance to celebrate the 30th Anniversary with all Penang Hospice Society staff.

The attainment of 30 years is a very significant stage in a human beings life because at 30, one is no more a child but a young person. The 30th birthday is special. Penang Hospice Society, turning 30 years old is a very significant milestone.

I hope Penang Hospice Society will grow from strength to strength and achieve its dream of having its own building in the near future.



I hope Penang Hospice Society will grow from strength to strength and achieve its dream of having its own building in the near future.

Lastly, I would like to take this golden opportunity to wish Penang Hospice Society:

*“Happy 30th Anniversary and Thank You, Penang Hospice Society.
Your help and service mean a lot to us.”*

A VOLUNTEER

By Dato' Dr Chan Kok Ewe

8 Amazing NGOs You Should Volunteer For In Penang (www.jirehshope.com), highlighted organisations that were worthy of being volunteered for. Among the eight mentioned was Penang Hospice Society which provides holistic medical care in the homes of patients with advanced diseases to alleviate suffering and pain in patients. Additionally the medical care is complemented with emotional and practical support, education in simple nursing care. Its services also provide opportunities in learning palliative care to those who need it, such as doctors and medical students.

What We Do

The Penang Hospice Society was registered in 2001 and functions as a charitable non-governmental organization in the community. Currently it provides holistic medical care in the homes of patients with advanced life limiting diseases, mainly cancer along with non- cancer patients. This service is called the Hospice at Home Program (HHP). A multi- disciplinary team of nurses, doctors visit the patient at his/her home to address the problems of the patient be they physical such as pain, psycho-social, or spiritual with the aim of reducing suffering while at the same time helping the family cope.

In the past three years we have cared for some 2,389 patients of which 1,704 were new. The onset of Covid during this time did not significantly affect the visits paid to the patients. The care was given free to the patients on the Penang Island and Mainland. The question is how is the service funded each year (just over one million ringgit in 2021).

Being an NGO, it is a voluntary group or institution with a social mission, which operates independently from the government. We depend on volunteering, contributions from the community, volunteer fund-raising events and including volunteer grants from the federal and state Governments. The monetary contributions are used to pay for the day-to-day running costs

There is yet another important aspect of running the service – the contributions of the time and effort of members of the society and its EXCO. This vital support is done willingly at no cost to the organization, thus giving the support to the Mission and Vision without any extra financial burden.

Why do People Volunteer?

We are the world

We are the children

We are the ones who make a brighter day, so let's start giving

There's a choice we're making

We're saving our own lives

It's true we'll make a better day, just you and me

With busy lives, it can be hard to find time to volunteer. However, the benefits of volunteering can be enormous. Volunteering offers vital help to people in need, worthwhile causes, and the community, but the benefits can be even greater for you, the volunteer. The right match can help you to find friends, connect with the community, learn new skills, and even advance your career.

Are You Ready?

There are various areas to serve

- i) Support for patients
This can include visiting and sharing work with home caregivers. Volunteers with necessary certification can also provide massage therapy and other appropriate complementary therapies.
- ii) Respite and support for family members
Volunteers can assist with shopping or light household maintenance, or allow family caregivers the opportunity to take care of necessary errands, exercise, or simply have some time alone.
- iii) Child care assistance
This can include help with babysitting, picking up children from school.
- iv) Bereavement support programs
Hospice volunteers can work closely with the hospice's bereavement activities. Duties may include assisting a support group facilitator, serving refreshments, or helping with mailings to families.
- v) Administrative work
A volunteer with clerical skills can serve a hospice by helping in the office with administrative duties.
- vi) Fundraising
Fundraising responsibilities are an important focus for maintaining and enhancing the services. These include organizing fundraising events, contacting potential donors and other initiatives to market the services attractively
- vii) Special skills and interests
Volunteers with special skills and interests may offer them to patients, their home carers and provide services to generate funds for running the service.



Caregiver by Ryann Huff

The heart of a caregiver is a rare element on earth
They define the true meaning and value of God's worth
The soul of a caregiver is precious and pure
Their spirits are heavenly, of that I am sure
The selfless compassion and love that they share
Provides relief, joy, and comfort just knowing they're there
Their efforts often unnoticed, full of strength and emotion
Bring peace to the heavens with angelic devotion
Many nights they are restless, their minds filled with unease
Because they devote their lives to tend to others' needs
There is none more deserving than one with the caregiver ability
They show peace, love, and mercy and give our loved ones dignity
Caregiver, a special place in heaven is waiting for you
There is a special place inside my heart that is reserved for you, too
Thank you for everything, all of it, and more
I pray someone so kind is there for you when you knock on God's door
You are loved and respected and cherished
And I wouldn't have known what to do without you

JUST RAMBLING - 1

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



Madam Mui in April 2022

The last 2 years have been difficult for all of us all over the world. Covid-19 has created havoc to every one in different degrees. Lives and livelihood have been drastically disrupted. Families have been separated. Businesses have closed, some temporarily, some permanently. Standard operating procedures keep changing in line with the latest situation causing a lot of confusion at times.



Hospice-at-Home volunteer doctor and a staff at work

Fortunately our Hospice-at-Home programme, established 30 years ago, in 1992, has survived this pandemic so far. Under the capable management of Dato' Seri Dr T. Devaraj, who established this praise-worthy programme and our dedicated staff our programme has continued to look after our patients.

Our doctors and palliative nurses used to visit the patients very regularly. Our nurses would teach family members and care-givers basic care-giving techniques, without interfering with the patient's medical requirements, prescribed by the patient's own doctor.

Now our doctors and nurses still continue to visit as well as keeping tabs by means of phone calls, in line with the current standard operating procedure.

We still loan out indefinitely, with no time limit and no payment, everything and anything, such as hospital beds, ripple mattresses, wheelchairs, walkers, commodes, whatever we have at that time to patients who need them, with the borrower bearing the transport fees.

Services through Hospice-at-Home programme had been completely free, from day 1. We used to receive some financial aid from Relay for Life, the signature fun and fund-raising activity organized by the National Cancer Society of Malaysia, Penang Branch until recently, when Penang Hospice Society which runs this hospice programme was expected to stand on its own feet.



We managed to survive through the generosity of the public, with some funds from the state government, local council and the federal government. These allocations have to be applied for yearly and they do fluctuate. We are indeed very fortunate that we have not had any staff layoffs or pay cuts so far.

We are blessed to have regular donors, especially amongst generous foundations which remember us yearly. Even at this current trying time, we have kind people walking in to Rumah Hospis, our base, to help us. Many donors have been touched by the wonderful help and service rendered to their loved ones. Moreover many readers of our Hospice Bulletin appreciate the great work the programme has been doing for the community.

Grateful thanks to Practical Printers, for the free art work and printing of our bulletin for many years. In addition we are given reams and reams of A4-sized paper that we need. The same privilege has also been extended to NCSM, Penang Branch as well. Incidentally the Managing Director was my class monitor in St Xavier's Institution 4 decades ago.



Penang Breast Care Society committee then together with the Governor's consort, Chief Minister's wife and VIPs at the Residency in April 1994. No recent committee photo available.

The Penang Breast Care Society, registered decades ago, based in Mount Miriam Cancer Hospital has been doing volunteer work for years. Sadly my friends and I have not returned to our posts there the last 2 years. We had a tea station manned by different volunteers on weekdays making hot drinks like milk, Milo and coffee for patients in the waiting room.

I used to be on duty every Tuesday to greet patients with a smile and a snack such as a curry puff or sandwich, hopefully to lessen the anxiety of the patients waiting for their turn for treatment or to see their oncologist. On the other 4 days, my friends would do the same.

After my rounds I would be in the Breast Care room, to meet patients, who wished to ventilate, to pour out their trials and tribulations. This confidential one-to-one "sharing" session has proven to be very therapeutic. The patient would feel much better having shared her inner feelings with one who had gone through the same predicament herself. Prostheses, wigs, scarves could be loaned out indefinitely. All these good services would be available again when the Covid situation is under control.



At the tea station, ready to serve drinks

Malaysians are very blessed compared to many other people in the world. Our government takes the necessary measures all the time unlike many countries where their citizens are left to do what they themselves think right, causing great chaos and more pain.

Doc finishes ultra-marathon to raise funds for hospice society

(Published in The Star, Metro news, Monday 02, May 2022)

INSPIRED by his late grandmother, a doctor in Penang ran a 250km ultra marathon in Sri Lanka in a bid to raise RM10,000 for Penang Hospice Society. Dr Jerry Song Zhi Liang, 27, ran his foot race from March 21 to March 27. "I used to volunteer at the hospice society and saw the many challenges it faced. "The society needs more support, especially for its home outreach programme," he said.

Dr Song's grandmother died in 2012 from pancreatic cancer. "Home hospice care gave her tremendous support in her end-of-life journey. I believe terminally ill patients have the right to die peacefully with minimal suffering," he said. Dr Song is no stranger to running ultra marathons to raise funds.



"This Sri Lanka ultra marathon is my third such event.

"I did my first ultra marathon in the Philippines in 2016 to raise awareness about cleft lip and palate defects.

"In 2017, I did the Xinjiang ultra marathon to raise funds for the Malaysian AIDS Foundation.

"It was a 250km seven-day race along the Silk Road in the Xinjiang province in northwest China.

"The route followed the Tian Shan Mountain range through the pastoral alpine countryside and across the Black Gobi Desert," he said.

Despite his busy work schedule, Dr Song found time to carry out his training which included hiking and jogging.

"I committed myself to a weekly mileage of 100km and above.

"I had to wake up at 5am on most days to train.

"My usual work schedule is from 7am to 10pm on long shifts; 7am to 5pm for day shifts and if I am on call, I will work from 7pm to 9am the next morning.

"I'm grateful that my superiors at work were supportive," he said.

Recounting his experience completing the Ultra X Sri Lanka, Dr Song said the scorching heat tested his endurance with the ground temperature between 35°C and 38°C at times.

"There were 53 participants and we ran an average of 50km throughout five days.

"On the first day, we covered 40km; 50km the second day and 50km the third day.

"The fourth day was the toughest as we ran 70km and we finished with 40km on the last day.

"I tried to maintain my pace at 10km in one and a half hours."

The Sri Lanka race took place in Udawalawe in the Ratnapura district in southern Sri Lanka.

The course took competitors past tea plantations and sugar factories and through rainforests and rushing rivers.

"I was thankful that the local children cheered us on and gave us water along the way.

"The course was very challenging and only 37 of us made it to the end," he said.

Anyone who wishes to donate to Penang Hospice Society can do so through the society's CIMB Bank account 8003864144.



Donors and supporters



Prudential donation of RM17,225.00



Damacai, also a constant donor of the society, donated RM15,000 in May



Donation from Lions Club of Penang Rising Star



Ms Jasmin Teh and friends donated disposables and milk for Hospice patients



Donation of diapers, hand sanitizers and wipes for Hospice patients from Ms Tan Gaik Ling, Ms Jocelyn, Ms Jessica Goh and Ms Molly Fong and friends

Celebrating our nurses and doctors Nurses Day get together - 25 May 2022



You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.
Dame Cecily Saunders



DEBUNKING THE MYTH OF HOSPICE CARE AND PALLIATIVE CARE A BLACK HOLE OF NO RETURN?

By Sukhveer Kawn

Many people I speak to about hospice and palliative care, their first thought is a place where people go to die. After getting involved in hospice and palliative care, I have always been interested in the topic of death and dying and the perception of many that it is meant only for those dying.

"One misconception about hospice care is that the care is only for the last days of life. The truth is that hospice patients can receive care for six months or longer, depending on the course of their particular illness. Patients benefit from personalized nursing care, medical equipment and supplies related to their terminal illness. Family members receive emotional and spiritual support, ongoing education about disease process and changing care needs, assistance navigating community resources, and grief support after the death of their loved one." <https://unityhospice.org/2020/01/14/hospice-is-only-for-the-last-days-of-life/>

Hospice and Palliative Care are places where I have learned a lot of spirituality and healing of the soul. I have enriched my knowledge about myself. I have learned how resilient I am and what are my expectations in life. This has made me more open in my approach with life and when I deal with patients and carers.

Discussing about death and dying is very healthy with your loved ones as one fine day, we will all say our goodbyes to our earthly plane, whilst the soul which was taking a ride on the earthly plane during the journey continues with the astral travelling (the plane which is the body will be cremated or buried according to the religious traditions).

Planning about our final journey of the earth body as the soul has its own journey and never dies. We have the right to choose what we want. We could be an organ donor or a body donor. How we want to be cremated: gas or firewood etc. All of this is just as important as our last WILL.

As usual we know everyone is going to depart from their earthly journey. Preparing the journey together with your loved ones is very important to give them the respect on how they choose it. It is very healthy to discuss about the choices we make.

Joyfulness, compassion and mindfulness can help a lot in the journey of a patient. We just cannot describe how we feel today or every day in a mix of emotions.

Laughter therapy in times of difficulty has helped make the situation relaxed a little as we are not laughing at the situation but as a form of relaxation and starting a conversation with the patient and family which ends up with a little humor but always a smile on their faces.

Why is closure very important in the patient's life for the patient to pass on peacefully, and for the loved ones to move on?

Closure is always important as patients have plans about something they have wanted to do which has not been accomplished. Helping them to do so makes the closure easier to allow the smooth transition to gradually move on peacefully.

Closure is always important as patients have plans about something they have wanted to do which has not been accomplished. Helping them to do so makes the closure easier to allow the smooth transition to gradually move on peacefully.

Why learning to let go and forgiveness is as important as gratitude?

Over the years when I learned on the importance of forgiveness, I learned the golden Mantra of "Ho'oponono. This Mantra is for all creations of the universe. Not only have I used it in my daily affirmations, I have used it with patients in counselling sessions and found it healing. Letting go of heavy weighing burdens from the chest.

Gratitude is very important by thanking the universe even in pain, sorrow, happiness and healthiness.

Gratitude becomes joyfulness. Joyfulness in any situation life is in leads to high spirits. This results in compassion which is very important for every creation of the universe.

**This is the mantra:
I AM SORRY
PLEASE FORGIVE ME
THANK YOU
I LOVE YOU**

"Ho'oponopono is an ancient Hawaiian spiritual practice that involves learning to heal all things by accepting "Total Responsibility" for everything that surrounds us—confession, repentance, and reconciliation".

"<https://www.compassionatelistening.org/post/power-of-wholeness-and-healing>



*"Death is not extinguishing the light; it is puffing out the lamp because dawn has come"
Rabindranath Tagore.*

In turn, I dedicate this recognition to the men and women of Penang Hospice - a diverse community of brave and resilient survivors, medical personnel including doctors and nurses, caregivers, staff and administrators, who attend to the needs and comfort of patients every day in their homes and at the hospice.

Death and dying is not easy. But it is the everyday acts of love, care, compassion and kindness of these extraordinary souls that make a meaningful difference. In our own ways, we can learn from their service and spread goodness with those around us.

PAIN

We recognize ourselves more when in pain because that is the time our anger, resentment, impatience comes out in terrible forms.

We also learn how to be patient, tolerant, acceptance of our condition and how to control our pain receptors so that it blocks out all pain.

Our pain is always the greatest pain. Look around us there are people who are in more severe pain than us. Feel their pain and you will find peace within yourself. Realization to understand your pain has a gift wrapped as a blessing in disguise.

The episodes of pain are actually betterment for us to heal as "pain heals pain" and makes us better. Everyone in life goes through different types of pain in their lives.

You either accept pain with tears or with a smile. Smile makes it easy to tolerate and accepting it. Tears and fears make it difficult.

The biggest pain is when we are alone, going through depression and loneliness. No one besides us when we die, that we can share a word or two before we depart.

The biggest joy of pain is forgiveness and thanking God with gratitude.

Start loving our pain and see how our body energizes, heals and mobilizes itself.

(Poem written during my stay in the hospital in 2010, during the time when I was in distress and feeling very down. This poem helped boost my spirits and motivated me.)

I dedicate this article and poem to my brother-in-law Prof. Dr. John Sibbald who I look up to in strength and resilience. Many a times we have discussed such topics whenever we met in Malaysia and New Zealand. Acceptance on his condition with Pancreatic Cancer last stage. To all on the final journey of realizing the LIGHT.

IN LIGHT WE COME IN LIGHT WE EMERGE



**TO EVERYONE IN THE UNIVERSE I RADIATE JOY,
LOVE, PEACE, COMPASSION AND LIGHT*
SUKHVEER KAUR*

The Ratu Kebaya 22, International Pageant is organised by the Kompleks Bukit Jambul to raise funds for charitable bodies



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2022
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International
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27th August 2022 | 7 PM
SPICE Arena, Penang *Ballroom 1*

For table booking, please contact
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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.

Change of address

Remove from mailing list

(please tick where appropriate)

Name: _____

Tel: _____

Fax: _____

Address (new): _____

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