



HOSPICE Bulletin



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

WORLD HOSPICE PALLIATIVE CARE DAY

Saturday 9 October 2021

By Dato' Seri Dr T. Devaraj

WHPC Day falls on the second Saturday of October. It began in 2005 as an annual event and along the way another older celebration - Voices for Hospice - which originated in the United Kingdom in 1991 was incorporated as a part but taking place only on odd years. While the latter (a celebration of hospice by song and dance) should be on this year it is very unlikely to happen in any country due to the covid epidemic. The lead for this event are two charities, namely the World Hospice Palliative Care Alliance (WHPCA) and Help the Hospices of the United Kingdom.



The 2021 theme is "LEAVE NO ONE BEHIND – EQUITY IN ACCESS TO PALLIATIVE CARE". Aspirational no doubt but it is a desire, an ambition as a guide to those who believe in the need for palliative care. The gap between the need and reality on the ground is huge, both globally and nationally. The "Global Atlas of Palliative Care", a publication of WHPCA stated this reality in 2017 – only seven million people had access to palliative care when the need was fifty million. Nationally it's the same with less than 10,000 given palliative care when over 100,000 ill persons need such care. Is there a national plan? Yes, it was launched in October 2019 as the "National Palliative Care – Policy and Strategic Plan 2019 - 2030" with the aspirational goal of "A nation Caring for Everyone Because They Matter". One notable feature of this plan was that it was a collaborative effort of both civil society and the government. On paper the plan is good and sets out achievable targets over the plan period. As the proof of a pudding is in the eating a plan will be measured by its outcome and that can only occur on implementation.

The planners were not stary eyed but realists who identified two key obstacles, namely political will and resources. Neither is unknown to those who are aware of national issues. One of the features of our system of democracy is that the term of a government is set at five years. So invariably those in power do tend to have short-term visions, along with a wholly reasonable desire to get elected again. For those in civil society who may feel aghast it is pertinent to point out that without power one cannot push along one's visions and hopefully deliver. This is a reality of how organisations function, be it government, businesses or NGO's. This is well known in public health where for instance one can believe in a tobacco-free environment it will take decades to achieve. As a matter of fact no country has achieved this goal thus far.

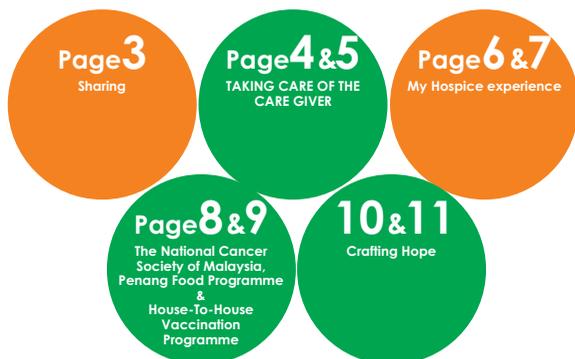


Adequate resources, say for health and health care has been an issue all over the world and we are not an exception with decades of calls by health professionals and civil society for more funding. The government has to ponder how to stretch the ringgit amongst many diverse needs and lobbies. While it can be a difficult juggling act, personally I feel that there are lessons from history, one being that putting people and the interests of the country as the focus, less mistakes are likely to result. We live, as many generations before us may have also characterised their times, in uncertain times, made worse by the current epidemic. At least for this epidemic there is light at the end of the tunnel, that is vaccination of all of humanity – and that's a huge task which the World Health Organisation, amongst others is spear heading. We can only hope they succeed for as our national call says – no one is safe till all are safe.



This is our scenario. So one may ask how relevant today is this year's WHPC Day theme. Equity in access means fairness. This is being realised in the covid vaccination strategy where apart from centres for vaccination a campaign has begun to go to the homes of those who wish to have the vaccine but are not able to access it. That community hospices are continuing to visit homes to help and support patients is an example of equity in access, especially as many who are ill are trying to avoid hospitals and clinics.

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HAPPENINGS:

• CARERS' MEETINGS_Via Zoom

Weekly review meeting with nurses
Thursday
Time : 9.00am - 1.00pm

• 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.

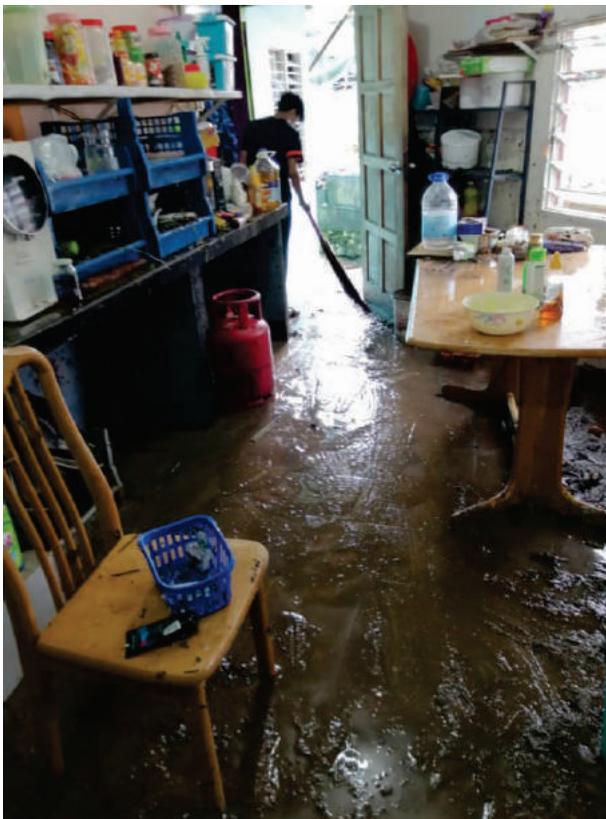
www.penanghospice.org.my
www.relayforlife.org.my
www.ncsmpenang.org

Sharing (Makna Support Group)

By Puan Azlina Abdullah

Pandemic, the word itself shows pictures of virus and disease spreading without control. Very true but the after effect on people especially the "Wiras" was another cup of tea as most "Wiras" are self-employed after losing their jobs on taking leave during their Cancer treatment. Usually it's a hand-to-mouth existence for most of them and a number of husbands also do daily-paid jobs as they were dismissed for taking too many days of leave during the wife's treatment. Thus the Pandemic left them foodless and a few were left homeless as they could not pay the rent and were chased out. Penang to top it, a kampong in Batu Feringghi was flooded after continuous rain and a couple of "Wiras" lost everything, the husband a kidney cancer patient with mets to the lung and the wife a breast cancer patient. They were overwhelmed with problems as one son met with an accident around the same time as the husband was diagnosed.

What little I could do to immediately help was to find cash funding and sundries for them to relief part of their burden. They are presently waiting for the Perkeso medical board to assist with pension ilat. We always think we are loaded with problems but there are so many out there with even more problems than us. May God bless this couple and relieve them of their pain and burden.



TAKING CARE OF THE CARE GIVER

By Tan Sri Gajaraj M Dhanarajan

The death and destruction of human lives and well-being brought upon by the ongoing corona virus – SARS 2 [or covid -19] also has at the same time drawn attention to the trauma being experienced by the range of workers populating the health sector including specialist doctors, interns, nurses, ambulance van drivers, cleaners, mortuary workers, ward attendants among many others. Many have paid the ultimate sacrifice with their lives, in the ongoing battle, the end of which seems to be nowhere in sight. These front liners have continuously been receiving tributes, accolades, modest monetary rewards, and simple expression of thanks from a grateful nation. Notwithstanding these courageous and dedicated workers, alongside them and almost unknown to others outside of immediate family, are thousands of informal family care givers (ICG), experiencing similar tribulations as their counterparts in the formal organized sector. While caring for a loved one, with a chronic condition, can be profoundly fulfilling it can also at times become a 'burden'. The PHS as well as its other fraternal organizations that provide palliative care to the terminally ill, rely on and work with family members during the course of their mission.

Estimates vary as to the size of the family care giving populations in the informal sector. Also uncertain is the range of multiple care-giving roles provided by the ICGs. These activities could range from the routine to the extraordinary – assisting with basic needs of daily living, housekeeping, monitoring medication, drafting, and managing a care plan as the illness or dependency progresses, meal preparation including feeding the patient, providing transportation to and from medical facilities as well as personal mobility. These varied and variety of tasks often fall on immediate and when circumstances permit extended family members who may also have the added responsibilities of earning a living. Not surprisingly, just as our health workers managing the current pandemic voice out their fears of 'burn out' and of PTSD (post-traumatic stress disorder), the ICGs by choice may suffer these in silence – very little is known of the stresses, strains and trauma of this population.

Recent academic studies about both physical and mental health of ICGs seem to indicate that the 'care giving burden', especially of those who have been tasked with palliative care, is a real and serious concern. In a recent study of some 249 informal/family care givers associated with a palliative care unit of a government tertiary hospital, researcher Zati Sabrina Ahmad Zubaidi of University Technology Mara [UITM] reported a range of physical, medical and psychosociological difficulties experienced by them. These included sleep disturbances, prolong fatigue, debilitating pain, loss of physical strength, loss of appetite and weight loss. Besides these, immune dysregulations and coronary artery diseases were also associated with their 'burden' leading up to depression, anxiety, and stress. If left unaddressed, the unintended impact of the burden will be even more on the care receiver.

While the PHS will continue to focus as much of its resources and energy to the care receivers, in time to come it may also have to expend an even higher proportion of its efforts on the informal family care giver. With Malaysia projected to see about 239, 713 of its citizens requiring palliative care by the year 2030, the demand and dependency on the informal care-giving-community is also expected to grow in tandem. The support they need will be as wide ranging as the support being given to their care receivers. Among the skills and knowledge they will require will include those items listed in Fig.1 as well as skills of observation, interpersonal communication, time management, organisation and an infinite amount of compassion as well as mechanisms to cope with personal grief.

Should PHS and its many affiliates show even greater attention to these unsung heroes?

'Zati Sabrina Ahmad Zubaidi, Famaza Ariffin, Cindy Teoh Cy Oun and Diana Katiman [2020]: Caregiver burden among informal caregivers in the largest specialized palliative care unit in Malaysia: a cross sectional study. In BMC Palliative Care (2020) 19:186

Ten Tips for Caregivers to Avoid Burnout

1. Become educated about the disease. The more you know about the disease, the more empowered and the more comfortable you will feel with role changes. Ask as many questions as you need to when you are in appointments. No question is a stupid question, and all questions are important.
2. Take care of yourself. As flight attendants say, "You must put on your own oxygen mask before putting on the mask of another." This philosophy stands for caregiving. If you are unhealthy emotionally, physically or spiritually, you will be of no help to any one else.
3. Practice healthy living. You are much more capable of being a help to others when you eat a healthy, balanced diet, exercise regularly, are involved with your own interests and get enough sleep.
4. Stay social. Connecting with others in similar situations is powerful, because you no longer feel isolated and you can learn from others. In addition, make sure you maintain other important relationships such as with children, family members and close friends.
5. Accept help. As difficult as it is to ask for help from others, realize that you need a break and that others may want to help. You do not have to do it all, nor is it healthy to do it all. The best way to avoid burnout is to accept help. People often want to help; just ask.
6. Acknowledge your emotions. If you are feeling hopeless, worthless, helpless, sad, anxious or fearful, acknowledge these emotions. These are all normal reactions to your situation.
7. Allow for healthy expression of your feelings with each other. Just because you are now a caregiver does not take away the fact that you had a relationship with this person in the past. You are still a spouse, partner, child, etc., and with that comes the responsibility to speak respectfully and openly. Should difficulties arise, seek couples or family counseling. Your multidisciplinary physician team will have a list of qualified mental health professionals.
8. Allow for caregiving holidays. This simply means taking some time away. You will be a better caregiver to your loved one if you do so.
9. Encourage healthy independence of your loved one. Help your loved one be as independent as possible for as long as he or she can. This may involve assistive devices or new technologies, so seek these out.
10. Seek help through your local organizations. Each territory or state has its own society or organization dedicated to a specific disease. You can find these in the United States by typing in the National (insert disease) Association of America in an Internet search engine.

*Sullivan, A.B. (2015):Who is taking care of the Caregiver. In Journal of Patient Experience. V2(1):7-12.

My Hospice experience

By Dr Regina Yeap – Palliative Care Physician, Penang Hospice Society

2014, we left cold and gloomy Manchester for tropical, food paradise Penang. As any migrant worker will know, deep in their hearts there is always the longing to be home. I was excited to begin our adventure of re-discovering my hometown, this time with my children. Working in England as a GP with a special interest in Geriatrics, I had to tailor my skill sets as best that I can to the local health system, my job simply doesn't exist here.



Dr Regina Yeap with Palliative Care Nurse Molly Lim visiting a patient at home. (Photo taken before Covid 19 era).

As a GP working covering Nursing Homes and very deprived areas in Kirby- with poly-drug and alcohol addictions, mental health disorders plus social deprivation, I have seen the unglamorous side to England and also the suffering and pain of those coming to the end of their lives. England is not all Harrods and the red double decker buses on Oxford street. I was eager to start working with the local patients, having spent all my entire working life looking at a different culture from the outside.

Penang Hospice society is a largely nurse-led, outreach service, staffed by a group of dedicated members who are both innovative and practical in their approach of working within the restricted resources we have. We are led by our nanogenarian medical director who had forged the existence of this service out of his own will and belief.

We cater to all creeds and across the social classes; from the wealthiest with personal maids and private nurses to those who lie down on a makeshift mangy undressed mattress. The well-to-do have medical care that extends beyond what makes sense at times, grasping at straws with exorbitant treatment, be it the latest pharmaceutical block-buster or thousand ringgit porcupine excrement that promises a too-good-to-be-true natural all cure with no side-effects. The poorest, we have to supply them with hand-me-down medications, without these they would be in a lot of pain and suffering. Much as our organisation aspires to gold standards of governance, medication wastage is sinful in the face of those who will suffer without it otherwise. We do what we can.

A large part of my job as a palliative physician is to help patients orientate themselves to what they are truly facing- terminal disease. Communication between the medical professionals from the government and private sector to us is often deficient, and I often, through the interpretation and understanding of the patient/ patient's relatives, have to piece together the extent of their diseases, the intended planned treatment, and help them make sense of it.

Many patients with curable diseases coming into our service, thinking they no longer had any other treatment options and the only way was to lie down to accept their faith; always citing that at a grand old age of 65, and they no longer need to extend their contented lives. They don't realise that many cancers these days have a prognosis that is more akin to chronic diseases. Sadly the under text for some of these is that the treatment would bankrupt the next generation. This is the harsh reality of not having a comprehensive national health service. Ironically, the geriatric department in the UK does not even begin to accept patients under their care unless you are above 73 years old. Wheeling healthy 90 year olds with a hip fracture for operation is bread and butter for anaesthetists on-call, while here they are left in immobility and suffer bed sores and pneumonia as a consequence. Some of these cases, I have had to accept the system as it is and be comforted that the patient is content in their decision and is well supported by a loving family.

One thing that struck me as different between the community care of patients here and in the UK is that there seems to be a disproportionate number of people in vegetative states being cared for, some for over 10 years. Decision to persist with life sustaining care is a medical decision in the UK while in Malaysia it is up to the relatives. There is a well-recognised professional body of acceptable rationing of treatment, not only for the sake of scarce resources but also for futile treatment which causes a lot of suffering at the end of a person's life with little benefit. Here in Malaysia there isn't. I often explain to medical students in my palliative lectures, just because a treatment is available, it doesn't mean it is the right thing to apply to everyone. The treatment is a tool to achieve your end. Advance Care Plans are not well recognised or practised by the professions here, nor does it have any legal standing. Often doctors go with relative's wishes, and those wishes are based on fears of suffering and mortality of the layman, not realising that a palliative natural death is equally a good option.

On the other hand I was much conflicted in a case where the family of a vegetative patient who has been cared for by her daughter-in-law for the past year had decided to remove her feeding tube once they realised there was no more hope of recovery for their mother. It can be argued that the family was exhausted and signs of fray were showing between the siblings. Should one stop feeding someone because the family is no longer coping with the care, or was this the right decision in the first place for someone with little hope of recovery. The answer lies in a murky spectrum between the best interest of the patient and that of the family. Professionally, there are no laws to guide us on the correct way forward. At the time I had spoken to various legal as well as medical professions to get advice on how our hospice can support the family in cases like this. I was aware that whatever we did, it would set a precedent for our hospice. Personally none of our staff felt we should prolong this patient's life without the benefit of for a better quality of life. On the other hand, is removing her life sustaining feeding tube murder? In the end the patient's feeding tube dislodged and we were then in a position to decide that re-introducing this treatment tool would be pointless in this case. Ethically this was an easier decision. Interestingly no more than 6 months later the UK has changed their law on this and it is now permissible for families who request for withdrawal for life sustaining treatment, with medical professional agreement to follow suit without applying to the courts for it to happen. As professionals when faced with difficult decisions, we sometimes hide behind the law and our body of professions, which can at times stop us from doing what is needed and compassionate.

In the UK, shared decisions about diagnosis and treatment are with the patient, it is a serious misconduct that can get one stuck off the medical practice if it is not adhered to. In Malaysia it is the family as a whole who decides for the patient. One gentleman I recall distinctly, the change of his face from anguish and fear of death to relief and resolution struck me as so sad and unnecessary. For the past months, he and his family were struggling to contain his illness and emotional distress, revealing itself in trivial conflicts. Underneath it all, he actually had very filial children, who despite their best intentions were creating a suffocating situation for their father. After exploring their expectations and concerns, it struck me that both the family and he were trying their hardest to put up a front that all was well when he was in actual fact failing physically from his cancer. I encourage honesty and better communication within the family and I was asked to break the news of his advanced lung cancer to their father, who they thought was not aware of his diagnosis. Little did they suspect that 6 months before they found out, he already knew he had advanced cancer. The patient kept the diagnosis from his family so as not to upset them. The next day after our big revelation, the patient was finally able to lie down and rest, not having to pretend to his family that he was still capable of getting up. Within 3 days he had passed away peacefully. Instead of spending time arguing about how much food to force him to eat, how many vitamins and supplements and medications to give him, and the fear of not giving him the pain medications should it harm him, they were able to keep him comfortable and in those moments, the family was able to share precious time with him and say their farewell.

One such instance, I was happily able to discharge one lady back to normal living, albeit with an amputated limb but still a reasonably good life and caring family. This lady had refused amputation of her lower limb, and was willing to accept the consequence of gangrene, pain and death. It harks back to scenes of battle sites where limbs are amputated without adequate anaesthesia, but surely not in present day Penang. It turns out there has been much miscommunication and misunderstanding between the patient and her doctors and she thought this was her only way. Having the time to explore her thinking, I was able to untease the knots and make her understand that she had better options. This has taught me how important our actions as doctors are, and what is considered trivial can be perceived by patients as very crucial.

I have been so privileged to walk with these families in their very private and crucial time in their life. As I have affected the families whom I have come across, helping them navigate the hard times, and helping them reframe how they see their lives to make sense and what is of value, they too have touched my life. I try to value that which is important to us from a perspective that our lives are but a blip in the space of time.

On a personal level I have met nursing colleagues who are new in their careers and sat through many journeys in the car with them learning about the challenges and aspirations for young families in our country. I have also learnt from stories the 'retired' nurses tell me about their triumphs in how they bucked the system and propelled their children to better opportunities than what they had, their pride and their regrets. I will certainly miss our Balik Pulau outreach which never fails to end with a good Char Koye Teow and Laksa meal.

I can see for myself the level of stubbornness one needs to have to face the naysayer; the affirmation that the outreach service is a worth while cause; the determination to follow one's beliefs and not accept the status quo. My respect and admiration for our founder who has tracked up this hill, inspiring all of us to follow suit.



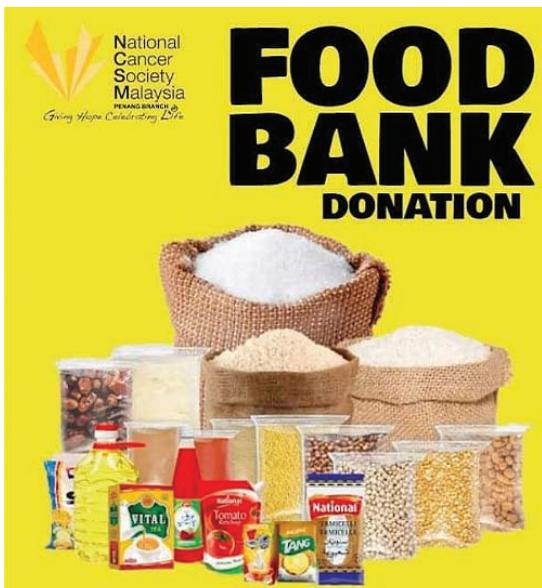
Dr Regina Yeap with Palliative Care Nurse Choke Ann Ann visiting a patient at home. (Covid 19 era).

The National Cancer Society of Malaysia, Penang Food Programme

Malaysia has enforced another lockdown on June 1 in order to control another surge of Covid infections. With another MCO extension which is now called "phases" of the National Recovery Plan, thousands of businesses have been shuttered or badly affected and many have lost their jobs, incomes and loved ones to Covid-19 pandemic.

Alongside with Bendera Putih Campaign created in June 2021 - which encouraged struggling Malaysians to raise a white flag so their neighbours can help – there are also food banks that provide basic necessities for affected individuals that often need replenishing of goods.

The National Cancer Society of Malaysia, Penang Food Bank Programme has started in July 2020 with some donations pledged by an anonymous donor. Other donors have also helped with cash donations and food items. The food items were delivered directly to their homes or they may arrange for self-pick-up at NCSM Penang's office. To this date, NCSM Penang Food Bank has benefited 41 patients and their families mainly from Penang Hospice Society and Friend of Childhood Cancer Northern (FOCCAN).



National Cancer Society Malaysia
PENANG BRANCH
Giving Hope Celebrating Life

FOOD BANK DONATION

We are raising funds for individuals / families with cancer or chronic illness who need food items / basic necessities. You can choose to donate food items or cash. Any donations will be warmly welcomed.

Contact us at 04-2284140 or 017-4804929 (WhatsApp only) if you need further information. Cash donations above RM50.00 will get tax-exempted receipts.

MAYBANK : 5070-5952-2230

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The National Cancer Society of Malaysia House-To-House Vaccination Programme

The National COVID-19 Immunisation Programme (NIP) or Programme Immunisasi Covid-19 known as PICK is a national vaccination campaign in curbing the spread of COVID-19. Malaysia is now preparing its people for an "endemic" phase of Covid-19 by the end of October, in which Malaysians will have to live with the virus and exercise self-responsibility. One of the key indicators to move to this phase is by achieving at least 80% of the vaccination completion rate.

However, traveling distance, limited access to medical providers or vaccine clinics, lack of public transportation and mobility issues make it hard for some people to get vaccinated. Mobile vaccination is one way to reach them.

Therefore, the National Cancer Society of Malaysia Kuala Lumpur with its Penang branch and the Penang Hospice Society has carried out house-to-house vaccination for bedridden patients living in the Kedah & Penang on the 15th & 16th September 2021. Representing NCSM Penang branch, were Cik Sari and Dr Bina Rai and from Penang Hospice Society, Wey Ah Aee, Esther Nirmalar David, Norhaslinda Othman and Gan Bee Loon. This mobile vaccination service caters to severely ill, bed-bound patients and people with special abilities – including those with cancer and other chronic diseases who are unable to travel to public vaccination centres.

This programme is an effort under the mobile clinic initiative of the National Covid-19 Immunisation Programme (NIP) as community-based programme to increase vaccination rates.

This 2 days' programme had mobilised its team to 48 identified houses in the efforts to protect vulnerable individuals who had difficulty making the trip to Covid-19 vaccination centres to get their jabs.





CRAFTING HOPE



Our mission

The purpose of this initiative is to shine a light of hope and happiness for people that most need it.

The name 'Crafting Hope' is to describe a personal connection through the medium of crafting and personalization. All our cards to the patients in Penang Hospice Society contain names of the sender and their personal messages addressed to the names of the patients themselves, along with a dried flower that signifies everlasting beauty. We serve as a medium for the goodness of the world to shine through and brighten a patients' day and to show them that they are loved, immensely. Even by people they may not know.

About our team !

Crafting Hope was founded by two aspiring doctors - Abigail Soo and Davina Loh. Both of us have experienced a family member navigating a cancer diagnosis and we have seen what they feel throughout the whole process. Cancer is not a simple affliction and there is no definitive cure, but we strive to provide comfort, hope, and love for all those who are going through this experience. Being a doctor might be the most direct way to heal someone but we must also consider the holistic aspect, which includes the patients' wellbeing. We believe that words of encouragement and reminders of love could bring hope and meaning to the life of each patient receiving our cards.

Currently...



Our team is growing as we expand our initiative and reach out to various institutions and enlarge our mission to encompass a much bigger demographic of people in need.

Contact us at craftinghopeinlove@gmail.com on email, [@craftinghopeinlove](#) on Instagram, or Crafting Hope on Facebook for any enquiries!

Collaboration

Macalister Mansion- Happiness In A Box



As of right now, we are collaborating with Macalister Mansion and have launched an initiative that entails a card being sent to a patient for each "Happiness in a Box" high tea set sold.

We are grateful to PHS, Macalister Mansion, and our volunteers for giving us the opportunity, assistance, and messages to provide hope to the patients in palliative care.

We hope that this and all future collaborations could benefit palliative patients of all countries and/ or situations and provide them with companionship even as we all go through this pandemic. We will strive to keep the initiative going even as the tide changes for the better and reach as many patients as we possibly can. We believe, firmly, that the joy in life lies in giving love to others.



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