



NEWSLETTER

Issue No: 05

MALAYSIAN ASSOCIATION OF PAEDIATRIC PALLIATIVE CARE

MAY 2020



*at MAPPAC,
where the child and the family matter!*

They need to learn that there is another way

Issue No: 05/003

MALAYSIAN ASSOCIATION OF PAEDIATRIC PALLIATIVE

MAY 2020

"I wish someone could've told me that there was another way, so that my child did not have to suffer," said a mother who had been taking care of her son with severe cerebral palsy.

Her 26-year-old son suffered from severe cerebral palsy since infancy, due to birth asphyxia. He was bed-bound and fed through a nasogastric tube for the past two decades. Curled up, he was only the size of a 12-year-old boy. Over the last two years, he was admitted several times due to episodes of coffee-ground vomiting. Endoscopy was attempted but failed due to his rigid body habitus, as a result of his contractures.

Would things have been different if he was managed with a palliative care approach when he was younger?

What could have been done for him?

- ◆ Child
 - Changing from nasogastric tube to gastrostomy tube when dysphagia is deemed permanent
 - Botulinum toxin injections to manage spasticity
- ◆ Mother
 - Caregiver training
 - Emotional and informational support
 - Advance care plan to guide the mother and relevant healthcare teams to manage the child during serious deterioration
- ◆ Coordination of care
 - Home healthcare team for home nursing and caregiver education
 - Medical social worker for equipment and financial aid
 - Rehabilitation team for home modification, physiotherapy
 - Dietician to review feeding regime



How can healthcare professionals provide palliative care for children if they have never been taught or exposed to it during their training? Awareness about paediatric palliative care (PPC) is still poor among healthcare professionals. Many myths and misconceptions regarding PPC result in missed opportunities to ensure a better quality of life for children with life-limiting illnesses.

Unfortunately, Malaysia has no structured curriculum for PPC in medical schools or other healthcare professions education. Postgraduate training for healthcare workers places slightly more emphasis on children's palliative care, but again, implementation is not standardized across different institutions. Clinical teachers find it difficult to complete teaching the 'must-knows' to their students with the available curriculum time. PPC ends up as a 'nice-to-know' topic which is taught sporadically. This results in a future generation of healthcare workers who miss the importance of PPC and fail to offer PPC as an option for children who need it. PPC needs to be made an essential part of healthcare professions education.

PPC can benefit life-limiting illnesses including cancer, end-stage organ failure, genetic diseases, and severe neurological conditions such as cerebral palsy. Much of the current teaching focuses on clinical management. Clinical teachers should also highlight the importance of comprehensive assessment and management, communication skills, inter-professional management, transition care and advance care plans. Healthcare students should be guided to reflect on these cases. Role plays to teach communication skills are also greatly beneficial by providing an immersive learning environment without potentially harming real patients during the learning process.

So, how do we respond if parents ask, "Why didn't anyone tell me about palliative care?" The actual question is: Are our healthcare professionals trained to consider PPC in managing children with life-limiting illnesses? It is time to incorporate PPC as an essential topic in healthcare professions education.



Article contributed by: Dr. Tan Chai Eng, Department of Family Medicine, Faculty of Medicine, University Kebangsaan Malaysia

Dr Tan Chai Eng is a Family Medicine Specialist and senior lecturer with UKM since 2011. Currently, she is advisor to the Home Care Unit of, UKM teaching Hospital, Hospital Canselor Tuanku Muhriz, which provides domiciliary nursing services to patients with restricted mobility.

Dr Tan teaches palliative care to UKM undergraduate medical students, actively using team-based learning approaches to deliver her sessions. Her area of interest is in home care, caregiver training and palliative care. She is one of the editors and a contributor for the National Handbook of Children's Palliative Care. She is also actively contributing to MAPPAC Home Companion Training Programme.

She will be pursuing her PhD in Health Education and Communication soon. She hopes that she can inspire her students to learn about palliative care and to empower caregivers to provide care for their children.

When a Child tells you he will soon die

Issue No: 05/004

MALAYSIAN ASSOCIATION OF PAEDIATRIC PALLIATIVE CARE

MAY 2020

As I entered into the house, I realized it was a shop-house. Mom asked if I could go into his room and wait while she finished the last part of sewing a baju raya. Both dad and mom were tailors and they were rushing to complete the Hari Raya's order. I opened the door and saw a 9-year-old boy concentrating on PS-1. I said hi and he grunted. I waited until he finished and when he did, he looked at me intensely and suspiciously. "Kamu doctor (Are you a doctor)?" he asked. I nodded. He continued with his game. Mom explained he had a congenital heart disease and his doctor told mom that he was entering into the terminal phase. They just wanted him to be comfortable towards the end. Observing him, the signs and symptoms of heart failure were obvious. I did not examine him that day. Just sat next to him, watching him played his games.

A week later I went back to see him again. He was not playing games because he literally 'burnt' the TV with his intense gaming. As I sat there, he asked, "Doktor, kamu nak tanya apa (Doctor, what do you want to ask)?" I asked him if he knew about his illness. He nodded. I asked if he knew it was serious, he nodded. "Saya akan mati tak lama lagi (I will soon die)," he said in a soft voice. I nodded. "Takut (Are you afraid)?" He replied, "Tak. Tapi sayang nak tinggalkan mak dan ayah (No, but hard for me to part with my mom and dad)" I felt a pinch in my heart. At such a young age, he had such understanding and love for his parents.

Weeks went by and we grew close. I learned why he loved his video games. He could longer able to go to school or his mengaji (prayer) class. That was how he passed his time. I once asked why he loved violent games. He said it was his way of releasing his anger. When he could beat the monster, he felt a sense of relief and the anger felt better.

It would be many more daring adventures that we had before he finally succumbed to his illness. Even towards the end, I was amazed by this child's tenacity. How he knew his time was short and yet tried to enjoy and have fun as much as he could before he went back to meet his Maker. Rest in peace my child because you had fought a good fight.

What have I learned from this young man? We should not dismiss how deep a child's understanding of their illness and miss the opportunity to talk to them about it. I learned that children have different ways of dealing with their emotions and we must be ready to learn from them. We must not be judgmental of the choices they made, so that our heart and mind are open to accept them just as they are and walk with them as their doctor and their friend.

This tiger toy belongs to my patient who was in hospital for treatment. He only felt better when his mom put 'bandages' to the paws. He could identified with the tiger's pain and felt better when he hugged it.



This article is contributed by Dr. Felicia Chang Chui Fun. Palliative Care Practitioner Beacon Hospital, Petaling Jaya.

Dr. Chang obtained her M.B.B.S. from Kasturba Medical College, India in 2000 and obtained her Graduate Certificate in Palliative Care from Flinder's University Adelaide in 2009. She has more than 19 years of extensive experience in Palliative Care having served in Ministry of Health, 2 Local Hospices and currently in Beacon Hospital. She is actively involved in various NGOs, among which are MAPPAC, MCPAM and KCBB.

Dr. Chang's area of interest and passion is in palliative care for children focusing on enhancing quality of life of children with life-threatening conditions and their families, which include physical, emotional and social, care and support.

She is also a speaker educating the public about palliative care, giving talks to various organizations to create awareness about important health issues. She has been invited to TED to speak about palliative care.

She was honoured as one of the "Ten Outstanding Young Malaysian (TOYM) 2015" and also bagged 2 awards from Women's Weekly "Great Women of Our Time 2015" – for categories: Health, Sport and Wellness and The Most Inspiring Women 2015. The Star Newspaper selected her as one of the 17 Persons of the Year for 2015 for her work in palliative care.

Dr. Chang's favourite quote:

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



I am an Angel Child ...



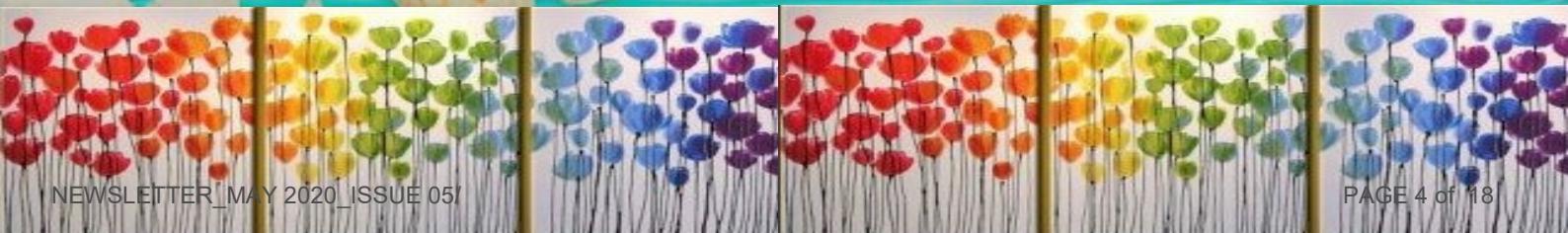
We would like to invite teachers and parents to encourage your children to do paintings or paint a card; to encourage children with life limiting disease, their family and health staffs.

With your encouraging words and beautiful artwork, they will not feel alone in the journey of care and fighting the disease.

MAPPAC will handle the delivery of artworks (paintings or cards) to the respective individual according to donor's requests.

Upon submission of paintings or cards, your child will be automatically enrolled as a member of our Angel Club. Your child will be eligible to join our other activities including Family Day, Children's Day, painting classes & etc.

All the donations will go towards setting up Malaysia's first children hospice care centre.





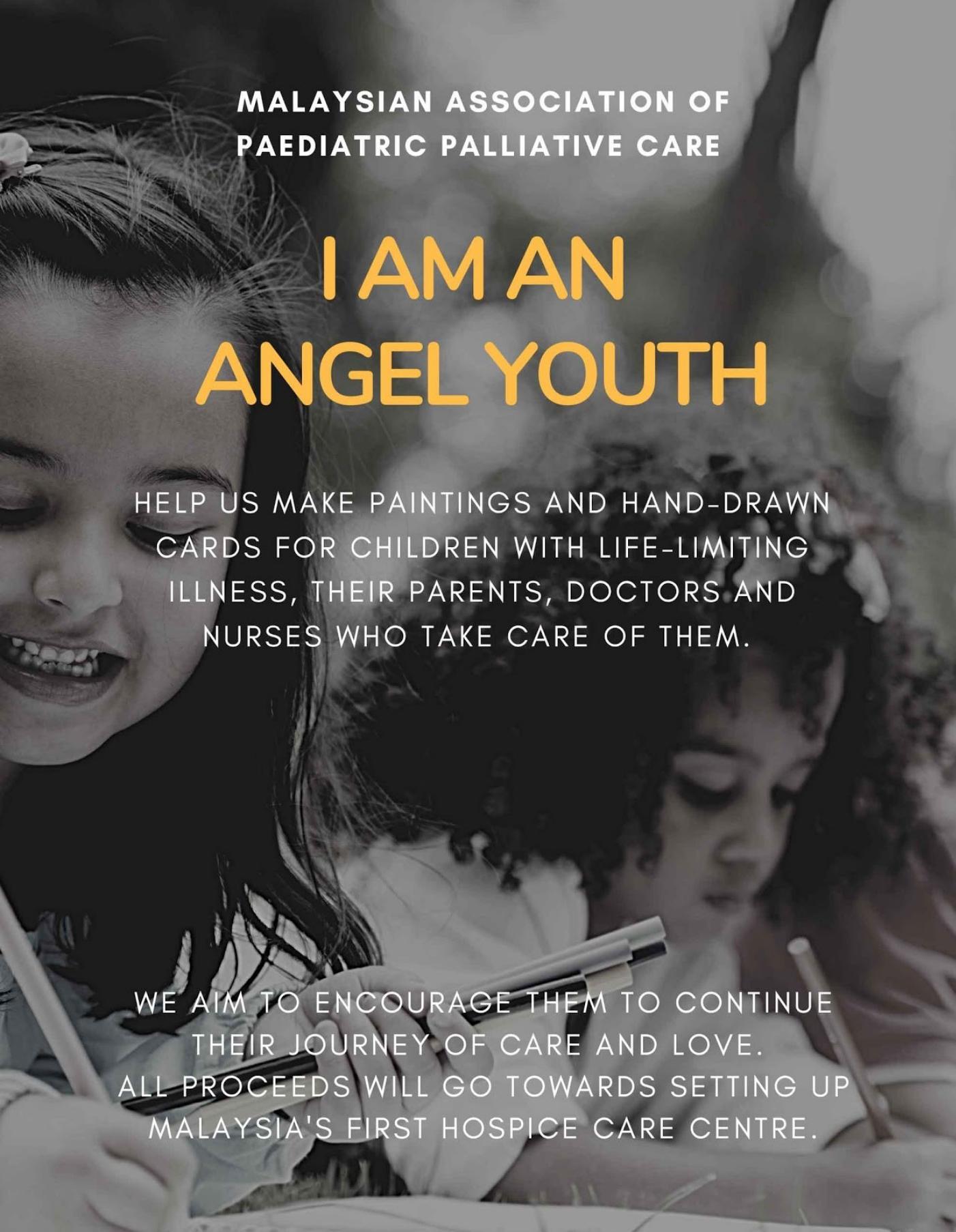
I AM AN ANGEL CHILD

Calling for children and youths to hand draw paintings and cards for:

1. Dying children
2. Parents of dying children
3. Doctors, nurses and medical staff who care for children with life-limiting diseases

We aim to encourage them to continue their journey of care and love. All proceeds from the sale of cards and paintings will go towards setting up Malaysia's first hospice care centre.

For further details, contact us at
mappacmalaysia@gmail.com | 0162231357



**MALAYSIAN ASSOCIATION OF
PAEDIATRIC PALLIATIVE CARE**

I AM AN ANGEL YOUTH

HELP US MAKE PAINTINGS AND HAND-DRAWN CARDS FOR CHILDREN WITH LIFE-LIMITING ILLNESS, THEIR PARENTS, DOCTORS AND NURSES WHO TAKE CARE OF THEM.

WE AIM TO ENCOURAGE THEM TO CONTINUE THEIR JOURNEY OF CARE AND LOVE.
ALL PROCEEDS WILL GO TOWARDS SETTING UP MALAYSIA'S FIRST HOSPICE CARE CENTRE.



For further enquiries, contact us at:
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Mereka perlu belajar bahawa terdapat

Isu No: 05/003

MALAYSIAN ASSOCIATION OF PAEDIATRIC PALLIATIVE

MEI 2020

“Kalaulah saya diberitahu bahawa ada jalan lain, supaya anak saya tidak perlu sengsara,” keluhan seorang ibu kepada seorang anak yang menghidap *cerebral palsy* yang teruk.

Anaknya yang kini berumur 26 tahun, disahkan menghidap *cerebral palsy* yang teruk sejak lahir, akibat kekurangan oksigen semasa lahir. Beliau terlantar dan diberikan makanan melalui tiub nasogastric dalam lebih dua dekad sebelum ini. Badannya meringkuk dan menyerupai budak berumur 12 tahun. Dalam dua tahun kebelakangan ini, beliau telah masuk wad beberapa kali kerana muntah darah. Endoskopi perut telah dicuba tetapi gagal disebabkan oleh postur badan meringkuk akibat otot-otot yang telah mengeras.

Adakah keadaan beliau sekarang mungkin berbeza sekiranya dia diuruskan dengan pendekatan jagaan paliatif semasa zaman kanak-kanak?

Apakah yang mungkin boleh dilakukan untuk beliau?

- ◆ Anak
 - Menggantikan tiub nasogastric kepada tiub gastrostomi apabila didapati adalah berkenaan
 - Suntikan toksin Botulinum bagi mengurangkan spastisiti (otot yang keras)
- ◆ Ibu
 - Latihan penjaga
 - Sokongan emosi dan maklumat
 - Pelan jagaan awal (advance care plan) bagi membimbing ibu dan pasukan perubatan untuk mengurus anak sekiranya berlaku kemerosotan kesihatan yang teruk.
- ◆ Penyelarasian atau koordinasi
 - Pasukan jagarawatan dirumah bagi prosedur jagarawatan dirumah dan pendidikan penjaga
 - Pegawai kerja social perubatan bagi bantuan peralatan dan kewangan,
 - Pasukan pegawai rehabilitasi bagi pengubahsuaian rumah, fisioterapi
 - Pegawai dietetic bagi memantau rejin pemakanan



Bagaimanakah kakitangan kesihatan boleh memberikan jagaan paliatif bagi kanak-kanak sekiranya mereka belum pernah diajar atau didedahkan kepada konsep ini semasa latihan? Kesedaran berkenaan jagaan paliatif kanak-kanak (PPC) masih lemah di kalangan kakitangan kesihatan. Banyak mitos dan tanggapan salah berkenaan PPC mengakibatkan peluang-peluang terlepas untuk menambahbaikkan kualiti kehidupan kanak-kanak dengan penyakit-penyakit yang menghadkan nyawa.

Malangnya, belum ada kurikulum berstruktur bagi PPC dalam pendidikan kakitangan kesihatan mahupun sekolah perubatan di Malaysia. Latihan pascasiswa bagi kakitangan kesihatan memberikan sedikit penekanan pada PPC, tetapi, pelaksanaan kurikulum adalah tidak seragam bagi institusi-institusi berlainan. Pengajar-pengajar klinikal menghadapi kesukaran untuk mengajar semua topik-topik “wajib tahu” kepada para pelajar dalam tempoh kurikulum yang tersedia. Oleh itu, PPC telah dijadikan topik “bagus untuk tahu” dan diajar secara oportunistik. Akibatnya, generasi kakitangan kesihatan masa depan mungkin tidak menyedari kepentingan PPC, justeru gagal untuk menawarkan PPC sebagai opsyen atau jalan lain bagi kanak-kanak yang memerlukannya. PPC perlu dijadikan sebahagian wajib dalam pendidikan kakitangan kesihatan.

PPC boleh memanfaatkan pelbagai penyakit yang menghadkan nyawa, termasuk barah, kegagalan organ tahap akhir, penyakit genetik dan penyakit neurologi yang teruk seperti cerebral palsy. Kebanyakan kandungan pengajaran sekarang menekankan pengurusan klinikal sahaja. Pengajar-pengajar klinikal perlu menonjolkan kepentingan penilaian dan pengurusan pesakit yang komprehensif, kemahiran komunikasi, pengurusan inter-profesional, jagaan transisi dan pelan jagaan awal. Pelatih kesihatan juga perlu dibimbing untuk merenungkan kes-kes tersebut. Pengajaran kemahiran komunikasi menerusi lakonan (role play) amatlah bermanfaat sebagai pembelajaran imersif tanpa menimbulkan risiko kemudaratan kepada pesakit sebenar semasa proses pembelajaran.

Akhirnya, bagaimanakah kita menjawab sekiranya ibu bapa bertanya, “Kenapakah saya tidak diberitahu berkenaan jagaan paliatif?” Persoalan sebenarnya adalah: Adakah kakitangan kesihatan dilatih untuk mempertimbangkan PPC sebagai opsyen pengurusan kanak-kanak dengan penyakit yang menghadkan nyawa? Adalah tiba masanya bagi PPC untuk diterapkan sebagai topik wajib dalam pendidikan kakitangan kesihatan.

Artikel ini disumbangkan oleh Dr. Tan Chai Eng, Jabatan Perubatan Keluarga, Fakulti Perubatan, Universiti Kebangsaan Malaysia.

Dr. Tan Chai Eng merupakan pakar perubatan keluarga dan pensyarah kanan dan telah bersama UKM sejak 2011. Pada masa kini, beliau merupakan penasihat kepada Unit Rawatan di Rumah untuk Hospital Pengajaran UKM, Hospital Canselor Tuanku Muhriz yang menyediakan servis domisiliari kepada pesakit yang mempunyai masalah pergerakan.

Dr Tan mengajar subjek rawatan paliatif kepada pelajar sarjana muda perubatan, secara aktif menggunakan pembelajaran secara pasukan dalam sesi beliau. Minat beliau adalah dalam penjagaan dan perawatan di rumah, melatih penjaga pesakit dan rawatan paliatif. Beliau merupakan salah seorang pengarang dan penyumbang kepada Buku Perawatan Kanak-kanak di Malaysia. Beliau terlibat secara aktif dengan Program latihan untuk MAPPAC ‘home Companion’.

Beliau akan melanjutkan dalam bidang Sarjana lanjut PhD dalam Pengajaran kesihatan dan komunikasi. Beliau berharap akan dapat menjadi sumber inspirasi kepada pelajar pelajar beliau untuk belajar tentang rawatan paliatif dan berupaya memperkasakan penjaga pesakit untuk membantu dan memberikan rawatan pada anak-anak mereka.



Di saat si kecil menyatakan dia akan pergi meninggalkan mu

Isu No: 05/004

MALAYSIAN ASSOCIATION OF PAEDIATRIC PALLIATIVE CARE

MAY 2020

Semasa memasuki rumahnya, aku tersedar ianya hanya sebuah rumah kedai. Ibunya meminta aku untuk ke bilik anaknya, kerana ketika itu dia sedang menyiapkan baju raya. Kedua ibubapanya merupakan tukang jahit dan mereka sedang bertungkus lumus menyiapkan tempahan hari raya. Aku membuka pintu dan melihat seorang budak lelaki berumur 9 tahun bermain PS-1. Aku menyapa 'Hi' dan sapaanku dijawab dengan dengusan. Aku menunggu sehingga dia habis bermain dan ketika itu dia melihat dengan renungan yang tajam dan mencurigakan. "Kamu doktor?" Dia bertanya. Aku mengangguk. Dia meneruskan permainan tersebut. Ibunya memberitahu bhawa dia mempunyai masalah jantung kongenital dan doktornya berkata bahawa keadaanya sekarang berada di fasa akhir. Ibubapanya berhasrat agar anaknya selesa di penghujung hayatnya. Daeipda pemerhatian, tanda tanda dan simptom kegagalan jantung itu agak jelas. Aku tidak memeriksanya pada hari tersebut. Hanya duduk bersebelahan dan melihat dia bermain permainannya.

Seminggu selepas itu, aku kembali menemuinya. Dia sudah tidak bermain permainannya kerana jemu dengan permainan TV yang berlebihan. Aku mendekatinya, dia menyapa, "Doktor, kamu nak tanya apa?". Aku menyeloroh, adakah dia mengetahui tentang penyakitnya. Dia mengangguk. Aku menyambung, apakah dia mengetahui penyakit yang dihadapinya ini serius, dia mengangguk. "Saya akan mati tak lama lagi," dia menjawab dengan nada yang lembut. Aku mengangguk lagi. "Takut?". Dia menjawab, "Tak. Tapi sayang nak tinggalkan mak dan ayah". Hati ku bagai dicubit. Pada umur yang begitu muda, dia sudah berupaya memahami keadaan dirinya dan kecintaannya kepada kedua ibubapanya.

Beberapa minggu berlalu dan kami menjadi semakin rapat. Aku mula belajar sebab kenapa dia menyukai permainannya. Dia sudah tidak dapat ke sekolah atau kelas mengaji. Itu adalah caranya untuk mengisi masa lapangnya. Aku pernah bertanya mengapa dia meminati permainan yang ganas. Katanya, itulah cara untuk melepaskan kemarahannya. Bila dia dapat menewaskan 'gergas' dalam perminannya, dia berasa lega dan kemarahannya berkurangan.

Ini merupakan pengembalaan yang sukar bersama sebelum dia kalah pada penyakitnya. Di saat akhir, saya kagum dengan ketabahannya. Dia mengetahui masa yang ada adalah singkat tetapi masih cuba untuk bergembira dan bersuka sukaan sebanyak yang boleh sebelum kembali menemui Penciptanya. Berehatlah dengan aman wahai anakku kerana kau telah berjuang dengan semangat yang tinggi.

Di saat si kecil menyatakan dia akan pergi meninggalkan mu

Isu No: 05/004

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MAY 2020

Apa yang boleh aku pelajari dari anak kecil ini? Kita tidak boleh mengetepikan kefahaman anak kecil tentang penyakit mereka kerana kita akan terlepas peluang untuk berbincang mengenainya. Aku melihat dari lensa ku yang kanak-kanak mempunyai cara pemikiran yang berbeza bila mendepani emosi dan kita perlu bersedia untuk belajar dengan mereka. Kita tidak perlu menghakimi apa kehendak mereka, harapannya hati dan pemikiran kita terbuka untuk menerima mereka seperti mana mereka itu dan mengembara bersama sebagai doktor dan kawan mereka.



Patung harimau ini adalah kepunyaan pesakit yang telah berada dihos-pital untuk rawatan lanjut. Dia secara psikologi merasa lebih baik apabila ibunya meletakkan balutan pada badannya. Dia dapat merasakan kesakitan pada harimau dan merasakan lebih baik secara psikologinya apabila beliau mendakapo nya.

Artikel ini telah disumbangkan oleh Dr Felicia Chang Chui Fun, perawat dalam rawatan paliatif, Hospital Beacon, Petaling Jaya..

Dr Chang berjaya lulus dalam bidang kedoktoran (MBBS) dari Kolej Perubatan Kasturba, India pada tahun 2000; di ikuti dengan Sijil Graduasi dalam bidang rawatan paliatif daripada Universiti Flinders di Adelaide pada tahun 2009. Dia mempunyai pengalaman yang luas dalam perawatan paliatif selama 19 tahun dengan khidmat di Kementerian Kesihatan Malaysia, dua hospis tempatan dan sekarang di Hospital Beacon. Beliau amat aktif dalam pelbagai pertubuhan bukan kerajaan, antaranya MAPPAC, MCPAM dan KCBB.

Minat dan kemahuannya dalam perawatan paliatif untuk kanak-kanak tertumpu pada usaha untuk meningkatkan kualiti kehidupan kanak-kanak yang mempunyai penyakit yang singkat jangka hayat, serta membantu keluarga pesakit, dan ini meliputi bantuan fizikal, emosi, sosial dan penjagaan serta sokongan pada pesakit.. Beliau juga merupakan seorang penceramah yang aktif membimbang dan menerangkan perihal rawatan paliatif kepada masyarakat dan terlibat dalam siri ceramah kepada organisasi luar untuk meningkatkan kesedaran tentang kepentingan isu-isu kesihatan. Beliau telah juga dijemput untuk bercakap di TED untuk bercakap tentang perawatan paliatif.

Beliau telah dinobatkan sebagai salah seorang daripada "Sepuluh Belianisan Terbaik Malaysia" pada tahun 2015 dan mendapat 2 anugerah daripada Mingguan Wanita dalam peraduan "Wanita Terbaik di masa kini 2015" – di dalam kategori Kesihatan, Sukan dan Kesejahteraan dan di anugerah sebagai tokoh wanita terbaik 2015. Surat khabar The Star telah memilih beliau sebagai salah seorang daripada 17 individu terbaik pada tahun 2015 sebagai penghargaan dalam bidang paliatif.. Perikan kata-kata Dr Chang

Anda penting kerana anda adalah anda. Anda juga penting pada akhir hayat anda dan kita akan cuba menolong anda semampunya, bukan sahaja untuk mati secara aman tetapi juga untuk hidup sebelum anda meninggal – Dame Cecily Saunders

The 1st National Conference of Children's Palliative Care Malaysia

Swiss Garden Hotel, Bukit Bintang, Kuala Lumpur

24th to 26th March 2021

Supporting from the beginning



Children's palliative care is about promoting the best possible quality of life and care for every child with a life-limiting or life-threatening condition and their family. Giving families real choice has been key to this approach: a choice of place of care; a choice of place of death; and a choice of emotional and bereavement support.

International speakers



Dr Chong Poh Heng
Medical Director
HCA Hospicecare Singapore

- Prognostication for children with life-limiting conditions
- Resources & funding for PPC services



Dr Rever Li
Consultant paediatrician
Tuen Mun Hospital, Hong Kong

- 2-step vs 3-step WHO analgesic ladder
- Managing symptoms of children with cancer



Ms Serene Wong
Palliative nurse
HCA Hospicecare Singapore

- Talking to children about death & dying
- Respite care programme



Ms Queenie Luk
Asst Professional Services Manager,
Children's Palliative Care Foundation,
Hong Kong

- Children with PPC needs from underserved communities
- Wish fulfilment



Dr Lee Chee Chan
Advance care plan
Perinatal palliative care
Non-invasive ventilation in PPC



Datuk Dr Kuan Geok Lan
PPC Milestones in Malaysia

Dr Chong Lee Ai

Pain refractory to opioids
Truth telling
Research in PPC



Ms Elaine Teo

My journey in community palliative care
Use of syringe drivers



Dr Fahisham Taib
How I started PPC service in my hospital
The art of using opioids



Dr Yang Wai Wai

Siblings – never leave me out
Dealing with fear & anxiety in children



Dr Sujatha Doraimanickam
Creative drama intervention

Symposiums covering symptom management, expressive therapy, transition care, end of life care, palliative nursing, voices of parents & patients



SCAN ME

For more details <http://www.nccpcm2020.com>
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SUNWAY
MEDICAL CENTRE

他们有必要了解还有其它的办法

Issue No: 05/003

MALAYSIAN ASSOCIATION OF PAEDIATRIC PALLIATIVE CARE

MAY 2020

“我多么希望有人能告诉我还有其它的办法，那我的孩子就不需要承受痛苦了”，一位长期照顾其患有脑性麻痹症的孩子的母亲如是说。

这位母亲的二十六岁儿子出生时因出现新生儿窒息（birth asphyxia），导致他自幼儿时期就饱受脑性麻痹症的折磨。这二十几年来，他都卧病在床，并且需要通过鼻胃管喂食。卷曲的身体，让他的体型只有像十二岁男孩般的大小。过去的两年，他因为呕吐咖啡样物（coffee-ground vomiting）好几次入院治疗。

医生尝试给他做内窥镜检查但却因其挛缩导致僵硬的身躯而无法进行。如果在他年幼时就得到安宁疗护，情况是否会有有所不同？

我们能为他做些什么？

- ◆ 小孩
 - 当症状变为永久性的吞咽困难，可以胃造口术代替鼻胃管
 - 注射肉毒杆菌毒素以缓解痉挛症状
- ◆ 母亲
 - 照顾者照护技巧训练
 - 提供情绪支持以及正确的资讯
 - 当孩子病情恶化，藉由预立医疗自主计划能帮助母亲及相关医疗团队更好地做出符合病人最佳利益的决定。
- ◆ 护理协调
 - 居家照护团队提供居家护理，以及教育照顾者照护技巧
 - 医务社工提供器材及经济上的援助
 - 康复护理小组协助改善家居及提供物理治疗
 - 营养师协助检查饮食计划



如果专业医务人员在培训的过程中从未学习或接触儿童安宁疗护，该如何要求他们提供此项照护呢？

专业医务人员普遍上缺乏儿童安宁疗护的意识。由于存在的迷思和误解导致他们错失许多确保病重儿童拥有更好的生活品质的机会。

遗憾的是，马来西亚的医学院及专业医疗教育并没有将儿童安宁疗护教育系统化。虽然医务人员的学士后培训稍加着重于儿童安宁疗护，但并不是所有的教育机构都统一推行。临床教师受限于现有的课时，使得教导儿童安宁疗护的必要性从“须知”沦落成偶尔传授“知多一点点”的额外知识。这就造成了下一代的医务人员错失了解儿童安宁疗护的重要性，继而致使他们在面对有需要的儿童时忽略了将之作为其一考量。因此，儿童安宁疗护需成为专业医疗教育体系中一个必要组成部分。

末期疾病如癌症、器官衰竭、遗传疾病及神经障碍（例：脑性麻痹症）皆能受惠于儿童安宁疗护。当前的教育多专注于临床管理。临床教师应同时着重全面评估与管理，沟通技能、跨领域团队合作照护管理、过渡期护理及预立医疗自主计划。再者，让医学生在指导下针对上述病情诊断进行应对。角色扮演也是有利的方法向医学生提供沉浸式教学环境来教导沟通技巧，以避免在学习的过程中对真实个案病患造成伤害的可能性。

话说回来，当家长问到：“为什么从来没有人告诉我安宁疗护？”时，我们该做何回应？事实上，我们该思索的问题是，专业医护人员是否受训于在照护病重儿童时将儿童安宁疗护列入考量之中？该是时候将儿童安宁疗护列入专业医护人员教育体系中一个必要组成部分了。

儿童安宁疗护照护主要向末期及垂危儿童病患及其家人提供高素质的生活与照护。马来西亚儿童安宁疗护协会（MAPPAC）冀望能在我国建造第一所儿童安宁疗护中心。为此，我们需要马币400万元来实现这个愿景。同时，我们也需要每年支付大约50万元以提供完善的医疗服务。我们盼望善心人士能支持我们达到这个远大的目标。而您的捐助，肯定能让我们给这些孩子最好的医疗照顾，同时也能持续支持他们的家人与社群。请支持我们完成这项宏愿吧！

文章贡献者：马来西亚科学大学医学院家庭医学系·陈彩瑛 副教授

陈教授自2011年以来一直是UKM (Universiti Kebangsaan Malaysia) 的家庭医学专家和高级讲师。目前，她是 UKM 教学医院 Canselor Tuanku Muhriz 医院的家庭护理部门的顾问，该医院为行动不便的患者提供住所护理服务。

陈博士博士为UKM本科医学生教授安宁疗护，并积极使用基于团队的学习方法来开展课程。她感兴趣的领域是家庭护理、照料者培训和安宁疗护。

她是《马来西亚儿童 安宁疗护 手册》的编辑之一和撰稿人。她还积极为 MAPPAC 家庭伴侣培志工训计划做出贡献。

她将很快攻读健康教育和传播博士学位。她希望她可以激发学生学习 安宁疗护，并授权照顾者为孩子提供照顾。



当有个孩子告诉你他将不久于人世

Issue No: 05/004

MALAYSIAN ASSOCIATION OF PAEDIATRIC PALLIATIVE CARE

MAY 2020

当我走进屋里，发现那是一个店屋。孩子母亲请我到孩子房间去等她，让她把正缝制的一件baju raya给完成。孩子父母都是裁缝师，当时正赶制开斋节的订单。我打开门，看见一个9岁的男孩正专注地玩PS-1。我向他问好，而他咕哝着回应了。于是我在旁等着。待他结束以后，用直瞪瞪而怀疑的眼神看着我问：“Kamu doctor?”（你是医生吗？）我点头。他继续打他的游戏。母亲说他患有先天性心脏病，医生告诉她说他的病情已到了最末期。他们只想让他舒舒服服地过完最后的日子。从观察中发现他心脏衰竭的迹象和症状挺明显的。当天我没给他做检查，就坐在他的身边，看着他打游戏。

一周后我再次去探访他。当时他没在打游戏，因为他正对着电视打游戏打得正激烈。“Doktor, kamu nak tanya apa?”（医生，你想问什么？）我问他是否知道自己的病情。他点头。我再问他是否知道自己病情严重，他又点头。“Saya akan mati tak lama lagi”（我快死了。）他轻轻地说。我点头。

“Takut?”（害怕吗？）“Tak. Tapi sayang nak tinggalkan mak dan ayah.”（不害怕。但是舍不得离开爸爸妈妈。）我的心揪了一下。小小年纪的他对生命就已经有如此真切的体认，对父母有如此深厚的爱。

数周过去了，我们越发亲近。我终于明白他为什么那么爱打游戏。他已经无法上学，也无法参加诵经班（mengaji class）了。打游戏是为了消磨时间。曾经我问他为什么喜欢暴力游戏，他说那是他泄愤的方式。当他成功将怪兽打败时，他的愤怒就能得到舒缓。

在他最终屈服于病魔前，我们或许还能一起经历了许多大胆的冒险。即使在生命的最后，我仍为他的顽强意志折服。明知时日不多，在回去见他的造物主之前，他依旧尝试着享受生活和享乐。安息吧，孩子。你打了一场漂亮的仗。

在这孩子身上我学到什么？我们不应该低估小孩对于自身病情的了解而失去与他们沟通交流的机会。我发现每个孩子面对自己的情绪时有不同的应对方式，我们应该时时准备好向他们学习。作为他们的医生和朋友，我们不应该判断他们的抉择，应开放我们的心灵和思想全然接纳他们，并与他们并肩同行。



这只老虎属于我留院治疗的病患。当妈妈将胶布贴在老虎的爪子上，他的情绪才得以缓解。他能够觉察老虎的痛苦，并在抱着老虎后情绪得到安抚。

本文由 陈翠芬医生提供。八打灵再也安宁疗护信标医院。

陈医生在 2000年从印度卡斯图尔巴医学院毕业 获得了工商管理学硕士学位；随后，她于2009年获得了Flinder大学阿德莱德大学的 安宁疗护 研究生证书。她在 安宁疗护 领域拥有超过19年的丰富经验，曾在卫生部，2个安宁疗护中心和目前在信标医院工作。她积极参与各种非政府组织，包括MAPPAC, MCPAM和KCBB。

陈医生的兴趣和热心领域是对儿童的 安宁疗护， 重点是提高有生命危险的儿童及其家庭的生活素质，包括身体症状，情绪和生活技能，照顾和支持。

她还是一位演讲者，对公众进行 安宁疗护 教育，并与各种组织进行了交谈，以提高人们对重要健康问题的认识。她曾经被邀请到TED演讲 安宁疗护。

她被评为“2015年马来西亚十大杰出青年”之一，并且还获得了《妇女周刊》颁发的“2015年我们时代最伟大女性”两个奖项，其类别包括：健康，运动和保健以及2015年最具启发性的女性。

陈医生最喜欢的名言：

“您之所以重要，是因为您就是您。您对人生的最后一刻至关重要，我们将竭尽所能，不仅帮助您和平地死去，而且好好的活着，直到死为止。”～塞西莉·桑德斯夫人



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 MAPPAC

RESEARCH

- focuses on:
- Medical, Nursing and Paramedical Management
 - Care Pathway
 - Psychosocial Care
 - Demographic Data Collection
 - Collaboration with other Health Centres

ADVOCACY

- 1) Raising Public Awareness/Fund-Raising
 - Website (www.mappac.org)
 - Forums/Meetings
 - Speeches
- 2) Media - Radio interview/TV show / Newspaper reports
- 3) Parental Information
 - Leaflet / Booklet

RESEARCH & AUDIT

Advocacy



CLINICAL SERVICES



CLINICAL SERVICES

- offers:
- Home Visits
 - Respite Care (parents' short break)
 - Hospice Care

EDUCATION & TRAINING

- encopasses:
- Workshop / Medical Conferences for Medical Professionals
 - Training our Caregivers and Volunteers



MAPPAC is formed based on the need of providing a platform for health care providers, parents and volunteers to actively involving themselves in providing total care to all children and family who are facing the life-limiting* and life-threatening **illness in Malaysia, following the recommendation by the World Health Organization (WHO) 1998 of the definition of Paediatric Palliative Care (PPC) :

Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.

It begins when the illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.

Health providers must evaluate and alleviate a child's physical, psychological and social distress.

Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited

It can be provided in tertiary care facilities, in community health centers and even in children's homes.

Why be a MAPPAC Member?
Join us, be a Member!



Contact us for more information:

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MAPPAC

What is PAEDIATRIC PALLIATIVE CARE (PPC)?

Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.

* Defined by: World Health Organization (WHO)

- ◆ PPC begins when illness is diagnosed. It begins when the illness is diagnosed, and continues regardless of whether or not a child received treatment directed at the disease.
- ◆ Evaluation and Alleviation Suffering Health providers must evaluate and alleviate a child's physical, psychological and social distress and suffering.
- ◆ Multidisciplinary Approach PPC can be provided in tertiary care facilities in community health centers and even in children's homes



Children's palliative care is about promoting the best possible quality of life and care for every child with life-limiting or life-threatening condition and their family.

At MAPPAC, we aspire to build the first children hospice in Malaysia. For this, we need RM 4 million to realize the vision. We also require a further RM500,000.00 yearly to run the vital care services.



We can only do so with the support of people like you. The money you donate will enable us to care for the children and to keep supporting the families and the community. Help us to cherish the good deeds.

Malaysian Association of Paediatric Palliative Care

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