

# NEWSLETTER

Issue No: 06

MALAYSIAN ASSOCIATION OF PAEDIATRIC PALLIATIVE CARE

JUNE 2020



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

# A Little Reminisce

Issue No: 06/005

MALAYSIAN ASSOCIATION OF PAEDIATRIC PALLIATIVE CARE

JUNE 2020



I remember him vividly for he was a 16 year old boy at the peak of his youth. He was a known "mat rempit" in his neighborhood and I was just delving into paediatric palliative care, my very first year. He was diagnosed with osteosarcoma, the most common primary malignant bone tumour in children and young adults. Despite radiotherapy and multiple lines of chemotherapy over the span of 1 year, the cancer remained aggressive. It had spread to his lungs and the primary tumour at his left knee started growing into a fungating wound, corrodng into half of his leg.

He was faced with the most difficult decision in his

life then. Doctors recommended amputation so that a prosthetic leg would allow him more mobility and independence for the remaining estimated 6 months to live. But that was exactly the dilemma, wasn't it? If he were to agree, it would seem as though he had "given up" and "no longer fighting the good fight" but if he declined, did that signify otherwise? Often unspoken than not, his reality could only be understood by himself and his family much later on. Seemingly nonchalant at the time, he chose not to commit to any decision. Preferring to keep to himself, it seemed hopelessness had taken root. He no longer wanted to leave home or see his friends.

When I first met him weeks later, I remembered thinking to myself that he was definitely a young man of a few words. His family welcomed me into their home. They were hoping for practical advice on how to care for him

as he was bedridden due to the unfortunate size of the tumour. I could see they were trying very hard to portray positivity through it all. We worked out plans for pain management, wound and nursing care at home as well as adaptation of mobility and creative ways of facilitating his independence around his home environment. We made progress through the months as setting small, short-term goals enabled him to achieve them. This had allowed him to realize that not all was lost. He managed a few foodie outings with his family and this, in turn, changed his attitude. He teased and joked often.

Perhaps by then, he also viewed me as a constant and harmless enough being to allow some moments of vulnerability to sneak through. They took me by surprise. He knew he didn't have long to live. Through his eyes, he knew what that meant for him and his family. Instead of

voicing out his feelings of acceptance, he saw that his family relied on his defiance so that they have the strength to cope with the same unspoken future. No words were needed. It was his way of protecting them. He felt comforted as he believed his family would be able to move on. At the same time, he needed to grieve for the little things in life and the future he would not have. I

held on to all the mixed thoughts, opinions and words I had in mind during those moments and decided to just listen to him. I told myself, that his needs to be heard were more important than mine. His request was to let him live his life the way he saw fitting, no matter how long that may be. He was in full control despite how messy things might have seemed at home.

That much was the love and sincerity he had for life and those around him. Palliative care believes in fostering hope. Palliative care advocates living and dying with dignity at the end of life. Do we truly understand all its forms? I had the privilege ; from a 16 year-old boy who taught me more than what words could define.

### **Palliative Care Management:**

Hope blossoms with:

- ◆ Presence of meaningful relationship
- ◆ Ability to feel light-hearted/humour
- ◆ Clear aims/goals
- ◆ Courage, determination and serenity (being in the present)
- ◆ Ability to recall positive memories
- ◆ Having one's individuality accepted and respected
- ◆ Finishing unfinished business
- ◆ Spiritual beliefs.

(Adapted from K. Herth 1995, 2011)

### **5 Ways To Communicate Better**



This article is contributed by Ms. Elaine Teo, Bachelor of Nursing (Hons)

Ms. Elaine Teo is a Palliative Care Practitioner (Nurse), graduated from the International Medical University (IMU) with a Bachelor of Nursing (Hons). Her career in palliative care started back in 2013. Currently, she is journeying with ASSISS Palliative Services (APS) under the umbrella of Assunta Integrated Social Services (ASSISS). With their mission and vision of providing healthcare services to the poor, Elaine's hope is to be able to reach out to more patients living in the outskirts of the city and to continue promoting and providing palliative care in the community.

While involved in clinical/operational tasks of APS as well as teaching/training in the Assunta College of Nursing and MAPPAC, Elaine aspires to complete her Master of Counselling and looks forward to continued growth and change in palliative care.



# A Difficult Conversation

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It was 3 in the morning, when I performed CPR for the third time on B. The parents were sitting on a bench at a faraway corner, stealing what few glances they could through the curtain to see what was happening. Behind the curtain all the frantic actions and efforts were happening, with the parents separated and isolated from the development.

B was a young 10 months old boy who had severe aortic regurgitation. About of sepsis worsened the condition and he was thus admitted to the Paediatrics Cardiac ICU. In the morning, the consultant cardiologist and I did an echocardiogram

graphy to assess his heart function. Staring at the screen, we saw how little blood was being pumped to the body while the rest backflowed into the heart. We knew that despite all the inotropes given to make the heart work harder, eventually it would tire out.

With a heavy heart we carried this news to the parents. The usual discussion ensued where we explained to them that B's prognosis was grim. We asked them whether they would want us to perform active resuscitation with CPR, and as expected their answer was yes. None of us had the heart to tell them the futility of it.

At 10 p.m. I was informed that B's heart had stopped. CPR was started immediately and Adrenaline was given. His heart started pumping again. The parents saw a glimmer of hope, while I prepared myself for a long

hard night ahead. At 1 a.m. as expected, the dreaded code was called. This time, the CPR was longer and the Adrenaline dose was higher. There were uncertainties in the parents' eyes. I remained silent, not sure of what to tell them at this point.

At 3.20 a.m. they were still sitting at the bench looking helpless and afraid. I stared at the large bruise in the middle of B's chest; center of the bruise was a smaller area of skin break, resulted from the repeated chest compressions. What had I achieved? Was there any good out of the harm that I had inflicted on B? At this point, he needed his parents to be with him more than me. I went over to the bench and brought the hard truth to the parents. I informed them that CPR was not going to change the inevitable outcome and that B needed them to be by his side, not me.

This time, I sat on the bench while they sat by the bed with B. The Mother was crying while the Father was holding her shoulder and silent tears rolled down his cheeks. The Mother started to apologize to B; for giving birth to him with a heart defect and for not being able to help him pull through. I wanted so badly to tell her that none of this was her fault but I knew this was their private moment. The Mother gradually calmed down and started to sing to B some nursery rhymes. What an intimate moment for the family,

while facing such a devastating outcome! It must have been their frequent sharing of such tender moments together at home for I saw the anguish melted away from the parents' eyes and replaced with acts of pure love.

At 4 a.m. B passed away; cuddled, loved and carried to heaven with the beautiful song of the Mother's voice. Dawn came when the paper works were done and they were ready to leave the ICU. Before leaving the Mother told me that they had picked a burial plot which was

large enough for 2 adults and a child, so that one day the family would be complete again. It was a long road to grieving and healing and I knew it had begun at that moment in time.

5 years have gone by but I still think of him very often. Equally memorable was the heartbreaking conversation that we have shared. I realised on that day that it was a conversation filled with compassion, empathy and honesty that brought about healing for the patient's



This article is contributed by Dr. Tan Ru Wei  
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Dr. Tan is consultant paediatrician in Columbia Asia Hospital, Klang. He is also actively involved in the advocacy of Paediatrics Palliative Care as well as Paediatrics Bioethics



I am an Angel Child ...



We would like to invite you (teachers and parents) to encourage the children to do paintings or paint a card; this noble act would serve to support and 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.

For every card or painting you have contributed, MAPPAC will handle the delivery of artworks (paintings or cards) to the respective children according to the donor's requests.

Purchase and sales of the cards/paintings are through our MAPPAC website. At the moment, we are at the painting recruitment stage.

Upon submission of paintings/cards, your child will automatically be enrolled as our Angel Club member with the eligibility to join our future activities such as Family Day, Children's Day, painting classes & etc.

Donations will be channelled towards the setting up Malaysia's first Children Hospice Care Centre.

For further information (guidelines), please leave your name and contact number to our MAPPAC Admin officer, Ms. Jacqueline through WhatsApp 016-2231357 if you are interested to participate in the painting/card designing.



## I AM AN ANGEL CHILD

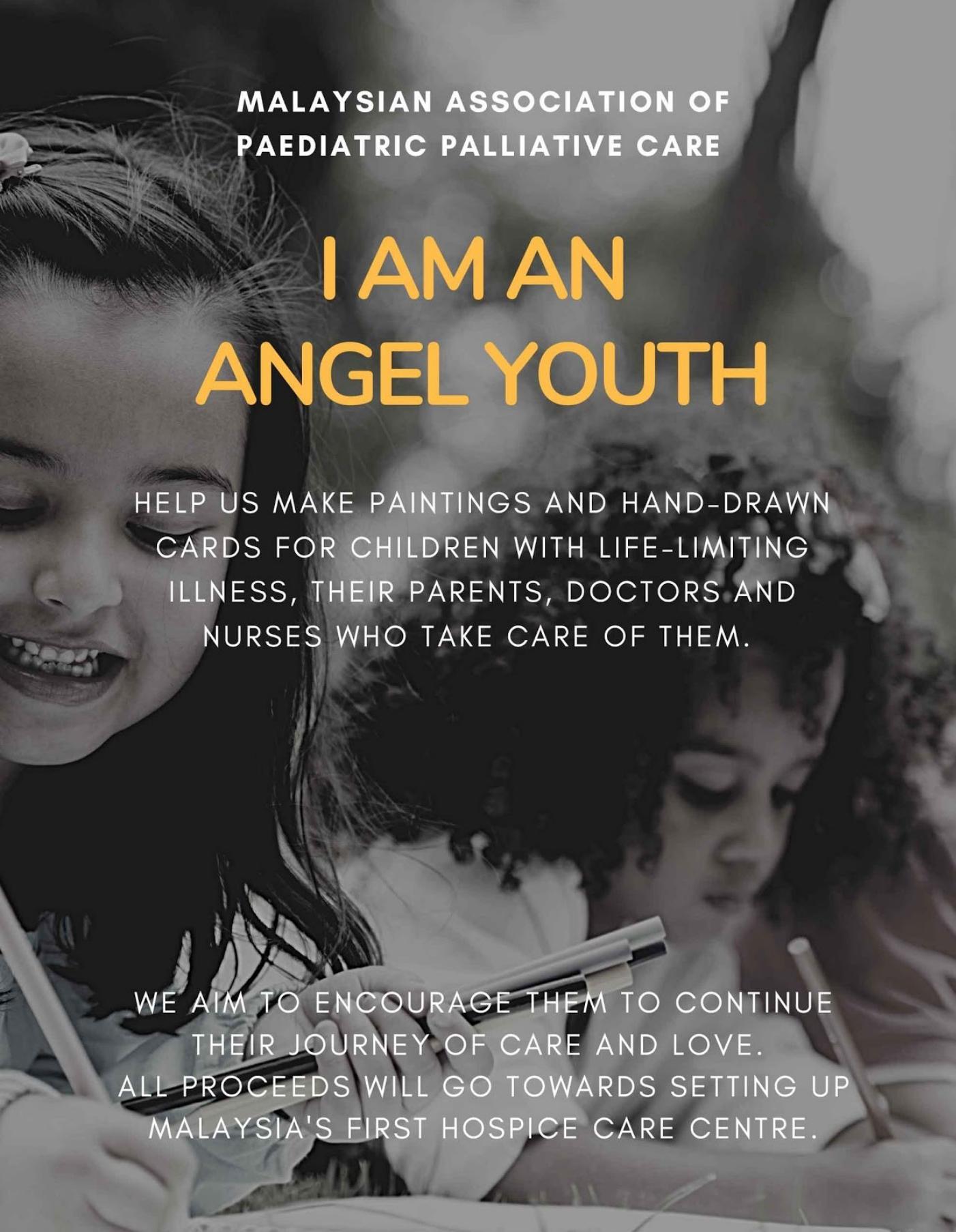
Calling for children and youths to hand draw paintings and cards for:

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](mailto: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:  
[mappacmalaysia@gmail.com](mailto:mappacmalaysia@gmail.com) | 0162231357

# Satu Peringatan

Isu No: 06/005

MALAYSIAN ASSOCIATION OF PAEDIATRIC PALLIATIVE CARE

JUN 2020



"Secara jujurnya saya masih mengingati dia sebagai seorang yang berumur 16 tahun dan berada di puncak zaman remaja beliau. Dia dikenali sebagai "mat rempit" di kawasan perumahannya, dan saya berada di tahun pertama dan agak sibuk dengan bidang perawatan paliatif kanak-kanak. Dia diagnos mengidapi osteosarcoma, iaitu kanser tulang yang paling agresif dikalangan kanak-kanak dan muda-mudi. Walaupun radio-terapi dan kemoterapi telah diberikan dalam jangka masa setahun, kanser itu tetap menjadi lebih agresif. Ia merebak ke dalam paru-parunya dan ketumbuhan asal yang berada di sebelah

lutut kirinya kini menjadi lebih besar dan menyebabkan luka yang parah, menghakis separuh kaki kirinya.

Dia berada di dalam keadaan dimana dia terpaksa mengambil keputusan yang sukar dalam hidupnya. Doktor menyarankan agar kakinya dipotong dan memakai kaki prostetik supaya dapat membantunya untuk bergerak tanpa kebergantungan pada orang lain untuk jangka masa kehidupannya selama 6 bulan lagi, tetapi itu bukannya dilema yang dihadapinya. Jika dia bersetuju, ianya seolah-olah bermaksud dia sudah mengalah dan tidak mahu melawan, tetapi jika menolak, adakah itu bermaksud sebaliknya? Biasanya perkara ini di tidak di bicarakan, realiti hanya boleh difahami oleh dia dan keluarganya. Dia seperti tidak mempedulikan masalahnya pada masa ini, dan dia bertindak tidak mahu memberikan apa-apa keputusan lagi. Dia

menyimpan rahsia di dalam dirinya seolah-olah harapan yang terputus telah berakar dan dia lebih suka menyendiri, telah kehilangan kehendak untuk keluar dari rumah dan tiada kemauan lagi untuk berjumpa dengan rakan-rakannya.

Selepas beberapa minggu, pertama kali saya berjumpa dengannya, saya merasakan dia adalah seorang remaja yang pendiam. Keluarganya menyambut baik kehadiran saya di rumah mereka dengan harapan untuk mendapatkan nasihat yang praktikal tentang cara penjagaannya kerana dia tidak bergerak akibat saiz ketumbuhan dan saya dapat melihat keluarganya menginginkan keadaan yang lebih positif. Kami bekerjasama untuk membantu dia mengawal kesakitannya, menjaga luka dan teknik penjagaan di rumah bersama dengan adaptasi untuk pergerakan dan mencari cara-cara yang

kreatif untuk tidak bergantung pada orang lain semasa di rumahnya. Selepas beberapa bulan, kami melalui fasa-fasa tersebut dengan jayanya, dengan meletakkan objektif jangka masa pendek untuk membolehkan ianya dicapai dan membantu dia menyedari bahawa tidak semua ikhtiar akan mengalami jalan buntu. Dia bekesempatan untuk keluar makan bersama keluarga, secara tidak langsung mengubah persepsi hidupnya. Dia menjadi seorang yang suka mengusik dan membuat lawak.

Dia merenung tepat ke arah saya, mungkin merasakan saya sebagai seorang yang tidak membahayakannya dan membiarkan dirinya diperiksa secara lebih mendalam. Saya sangat terkejut dengan perubahan ini. Dia tahu yang kehidupannya agak singkat. Pandangannya, dia menyedari masalah yang tersirat dan begitu juga keluarganya juga telah maklum akan dirinya. Dia memberitahu tentang perasaannya, untuk menerima hakikat sebenar, namun keluarganya masih menafikan keadaannya dan masih menaruh harapan, agar mereka mempunyai kekuatan

untuk melalui masa depan yang sukar diperkatakan. Tiada perkataan yang perlu diucapkan. Hanya itu saja caranya untuk mencegah daripada kekecewaan. Dia lebih merasa lebih selesa dengan keadaanya, kerana pada firasatnya, keluarganya boleh meneruskan kehidupan mereka tanpa dirinya. Pada masa yang sama, dia memerlukan masa kerana kesedihannya tentang perkara-perkara yang tidak dapat dilakukan dalam kehidupannya serta masa depan yang dia tidak akan lalui. Pemikiran saya bercampur baur, pandangan dan perkataan yang bermain dalam benak fikiran, saat ini merasakan adalah satu keperluan untuk mendengar luahannya. Keperluannya lebih penting dari keperluan saya, saya bisikkan pada diri saya. Permintaannya - biarkan dia hidup sebagaimana yang dia fikirkan tanpa memikirkan jangka waktu. Dia perlu merasakan untuk mempunyai keupayaan menetapkan hidupnya walau-pun keadaan sekeliling agak kucar kacir di rumah.

Itu adalah kecintaan dan kebenaran yang ada pada hidup dan sesiapa di kelilingnya. Rawatan paliatif

perlukan pengharapan. Rawatan paliatif menyokong konsep kehidupan dan kematian secara baik di akhir hayat. Adakah kita percaya tentangnya? Remaja 16 tahun ini telah mengajar saya lebih dari ucapan atau perkataan, yang boleh memberi makna.

### **Rawatan paliatif**

Usaha bermula:

- Dimulakan dengan hubungan yang bermakna
- Kebolehan untuk berinteraksi secara baik.
- Mempunyai objektif yang baik
- Keberanian, kehendak dan keamanan.
- Kebolehan mengingati memori yang positif
- Menerima seadanya dan menghormati penerimaan individu.
- Menyelesaikan permasalahan sendiri.
- Mempunyai pengetahuan spiritual

## 5 cara untuk berkomunikasi dengan lebih



### Mendengar secara Aktif

Berwaspada, mendengar dengan penuh tumpuan. Jangan mengganggu ketika seseorang itu sedang bercakap. Fokuskan pikiran anda pada apa diperkatakan.



### Maklum-balas

Saya nyatakan maklum-balas, dan bukannya tindak-balas kerana anda tidak seharusnya memberikan jawapan atau menyatakan pandangan pertama, apabila terlintas di benak anda. Luangkan masa, pastikan pemikiran kita jelas, kemudian beri maklum-balas.



### Penilaian/Bias

Adalah penting anda menjauhi tabiat 'bias' atau mempunyai persepsi terhadap orang atau topik perbualan. Cuba simpan emosi semasa mendengar.



### Bahasa Tubuh

Sama ada anda mendengar secara aktif, atau menilai seseorang secara senyap, ini akan ditunjuk dengan cara anda duduk, postur badan, pembahagian berat badan anda. Oleh itu, berhati-hatilah dengan gerak-geri/sikap anda.



### Soalan

Menanyakan soalan yang relevan adalah penting kerana ia menunjukkan bahawa anda mendengar dengan teliti dan aktif dan jika anda salah faham tentang sesuatu, kamu boleh menjelaskan sebelum menjawab soalan tersebut.

This article is contributed by Ms. Elaine Teo, Bachelor of Nursing (Hons)

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# Satu Perbualan yang Sukar

Isu No: 06/006

MALAYSIAN ASSOCIATION OF PAEDIATRIC PALLIATIVE CARE

JUN 2020



Jam menunjukkan pukul 3 pagi, ini kali ketiga saya terlibat dalam resusitasi ke atas B. Ibubapanya duduk di atas bangku di sudut yang tidak berjauhan, cuba men-curi pandang andai mereka dapat melihat apa yang berlaku di sebalik tabir. Di dalam tabir, semua tindakan ke-cemasan cuba di lakukan, dimana ibubapa B berada di luar tabir.

B merupakan seorang kanak-kanak lelaki berumur 10 bulan, mempunyai masalah jantung dikenali sebagai aortic regurgitasi. Beberapa episod jangkitan kuman menyebabkan tahap kesihatannya menurun, dan dia telah dimasukkan ke Unit Rawatan

Kecemasan Jantung bahagian Paediatric. Pagi itu, ketua bahagian perubatan jantung kanak-kanak dan saya. Bersama membuat echo-kardiografi untuk menilai jantungnya. Melihat kepada paparan skrin, kami dapat betapa sedikit darahnya dipam ke seluruh badan dan selebihnya memasuki jantung, kami mengetahui walau apa pun usaha kami seperti memberi ‘inotrope’ akan menyebabkan jantung bekerja lebih kuat tetapi selepas itu ia akan menjadi terlalu lemah.

Dengan berat hati kami memberitahu perkhabaran yang tidak baik kepada ibubapanya. Perbincangan berlaku, kami menerangkan dimana prognosis B yang tidak baik. Kami bertanyakan ibubapanya jika mereka mahu kan resusitasi dengan CPR jika jantungnya berhenti, dan jawapan mereka adalah ‘ya’

seperti yang dijangkakan. Tidak ada sesiapa antara kita sampai hati untuk memberitahu mereka tentang tindakan itu adalah tidak bermakna.

Jam 10 malam, saya dikejutkan dengan panggilan kecemasan dimana jantung B sudah berhenti. Resusitasi dimulakan, dan adrenalin diberikan. Jantungnya kembali berdenyut. Ibubapanya melihat keadaan ini dengan penuh harapan walaupun pada hakikatnya peluangnya amat tipis, saya sudah bersedia untuk menghadapi malam yang panjang lagi sukar. Jam 1 pagi, seperti yang dijangkakan saya dikejutkan lagi dengan panggilan kecemasan lagi. Kali ni, resusitasi menjadi lama, ubat adrenalin diberikan dengan dos yang lebih tinggi. Tidak ketentuan dibenak fikiran ibubapanya barangkali, Saya terdiam, tak tahu apa yang patut saya luahkan pada waktu ini.

Jam 3.20 pagi. Ibubapa B masih duduk di atas bangku, kelihatan tidak bermaya dan suram. Saya merenung ke atas lebam di atas dada B, di tengahnya ada kesan luka, mungkin daripada resusitasi dan tekanan CPR ke atas dada B sebentar tadi. Apa yang saya telah capai? Adakah kebaikan daripada apa yang saya buat ke atas B? Dia hanya memerlukan ibubapanya untuk bersamanya, bukan saya. Saya keluar menghampiri ibubapa B dan memberitahu apa yang wajar pada mereka. Saya beritahu bahawa resusitasi tidak akan mengubah apa-apa yang lagi. Saya menambah bahawa apa yang perlu untuk B ialah untuk ibubapa berada disisi B, bukan saya.

Kali ini, saya duduk di atas bangku sementara ibubapa duduk disisi B. Ibunya menangis, bapa pula memegang bahu si ibu, sambil air mata mengalir laju

dipipinya. Kemudian ibunya memohon maaf pada B, kerana melahirkannya dengan masalah jantung, dan tidak dapat memberi pertolongan kepada B. Saya mahu saja menyapa bahawa, semua itu bukan salah ibunya, tapi saya faham ini adalah kepentingan masa untuk bersama B. Secara perlahan, ibunya menjadi tenang dan menyanyikan beberapa lagu kegemaran B. Ini merupakan saat-saat yang penting bagi keluarga, dalam menghadapi dugaan yang besar! Ianya merupakan masa yang sangat berharga untuk keluarga bersama, saya dapat menyaksikan segala penderitaan ibubapa hilang daripada kenyataan, ini diganti dengan cinta sejati.

Pada jam 4 pagi, B meninggal dunia ini, dalam pelukan kasih sayang, dengan dendangan lagu yang merdu dari ibunya mengiringi B ke syurga dengan. Subuh menjelang,

semua kertas kerja telah siap dan mereka sudah bersedia meninggalkan ICU. Sebelum pergi, ibunya memberitahu saya yang mereka telah memilih tempat pengbumian, sesuai untuk 2 orang dewasa dan seorang anak, semoga satu hari nanti mereka akan di satukan kembali. Namun saya yakin, pengalaman ini akan menjadi satu perjalanan keluarga B lalui dengan berkahung dan selepas itu bersedia untuk keluar daripada kesedihan ini.

Ianya berlaku 5 tahun lepas, dan saya masih memikirkan tentang B lagi. Ianya adalah satu perbualan yang sukar tetapi pada hari tersebut saya mengerti apa itu belas kasihan, empati dan kejuruan, ianya akan menjadi perantaraan yang akan membawa pada kesembuhan, untuk keluarga pesakit dan juga doktor.



This article is contributed by Dr. Tan Ru Wei, MBBS (IMU), MRCPCH (UK); PEDIATRICS BIOETHICS (US), Consultant Paediatrician, Columbia Asia Hospital, Klang

Dr. Tan is consultant paediatrician in Columbia Asia Hospital, Klang. He is also actively involved in the advocacy of Paediatrics Palliative Care as well as Paediatrics Bioethics.

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

Swiss Garden Hotel, Bukit Bintang, Kuala Lumpur

24<sup>th</sup> to 26<sup>th</sup> 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



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

**Dr Sujatha Doraimanickam**  
Creative drama intervention



SCAN ME

For more details <http://www.nccpcm2020.com>  
Contact us at: 016-223 1357 (Jacqueline, MAPPAC)  
Email: [nccpcm2020@gmail.com](mailto:nccpcm2020@gmail.com)

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**SUNWAY**  
MEDICAL CENTRE

# 一段小往事

Issue No: 06/005

MALAYSIAN ASSOCIATION OF PAEDIATRIC PALLIATIVE CARE

JUNE 2020



我对他的印象特别深刻。当时16岁的他，正值青春年华，而当时的我是第一年刚涉足儿童安宁疗护。他在邻里中有个外号叫“mat rempit”（意即飙车族）。他被确诊患上骨肉瘤，是常见于小孩及青少年患者的一类原发性恶性骨肿瘤。尽管接受了超过一年的放射疗法及多次的化疗，癌细胞仍旧活跃，并且已扩散至肺部。他右膝的原发肿瘤已逐渐出现肿瘤溃疡，侵蚀了半边的腿部。

那时，他正面对人生最艰难的决定。医生建议截肢，因为安装义肢让他在剩下的6个月里能够独立并且增加可活动性。但这着实使人陷入矛盾，可不是吗？如果他同意了，不就等同于放弃及不再对抗病魔？但如果拒绝了，情况又有何不同？显然的，他的处境只有他自己和家人能够理解。他表面看似平静，并且选择对此决定不做任何的表态。他隐藏自己内心的想法，绝望似乎已在他的内心扎根。他拒绝出门，也不再会见他的朋友。

第一次见到他是几个星期后的事，印象中他是一个沉默寡言的少年。他因肿瘤肿大而需卧病在床。他的家人非常欢迎我的到来，并期待我能给他们带来实际的建议来帮助他。我能看得出来家人们想要积极地面对眼前的一切。我们制订了一套计划，这包括疼痛管理、伤口及居家护理、新适应活动方式、旨于居家环境中协助他自立的创意方式。几个月下来，我们帮助他一步一步地达成小而短期的目标，好让他能够意识到他其实并还未失去一切。这期间他和家人一块出门享用美食，这大大地帮助他并令他开始改变。他变得常要笑和开朗了。

或许从那时候起，我已成为他忠实而温和的陪伴者，能够偶尔窥探他软弱的一面。我惊讶于我所观察到的事。他自知将不久于人世。从他眼神中看得出来，这样的认知对他和家人意味深长。对于可预见的未来，家人是凭借着他对抗病魔的顽强因而有了面对的力量，因此他选择了将内心已经接受现实的感受给隐藏了起来。个中原因不言而喻。这是他守护家人的方式。他怀着信心相信他的家人能够在往后的日子好好地继续前进，让他感到安心。

但与此同时，他需要一些空间来为他再也无法拥有的生活中的大小事以及未来，表达出内心的伤感。我抑制住自己脑海里混杂的思绪、建议和说辞，决定专注地聆听他的倾诉。我告诉自己，让他的内心能够被听见远比我的需要更重要。不管未来剩下的日子还有多长，他都希望过着自己想要的生活。不管他的病情如何打乱了他们家庭的生活，至少他仍拥有对自己生活的掌控权。

这是他对生活和周遭的人的爱与诚意。安宁疗护主张建立希望，同时也提倡在生命的最后依然能有尊严地活着及有尊严地离世。但我们是否真正了解其中的核心概念？一个16岁的男孩所教会我的事远远超过文字所能表达的。

### 安宁疗护服务

希望萌芽于：

- 有意义的关系
- 感受轻松及幽默的能力
- 清晰的目的/目标
- 勇气、意志力及宁静（活在当下）
- 能够回忆起美好的回忆
- 人格被接纳及尊重
- 完成未完成的事
- 精神信仰

(改编自 K. Herth 1995, 2011)

### 五个方法让沟通更有效



Ms. 张秋雁 是安宁疗护医护人员（护士，毕业于 International Medical University (IMU)，获护理学荣誉学士学位。她于2013年加入安宁疗护的服务，目前任职于 ASSISS Palliative Services (APS)，隶属于 Assunta Integrated Social Services (ASSISS)。他们的任务和愿景是给贫穷者提供医疗服务。Elaine希望能够给更多住在城郊的病人提供服务，并且在社会上持续地推动及提供安宁疗护照护。

除了在 APS 提供医疗服务，张秋雁 也同时在 Assunta College of Nursing 和 MAPPAC 参与培训及教育工作。不仅如此，她还立志完成辅导硕士学位，并期望能在安宁疗护领域中成长及改变。



# 当有个

Issue No: 06/006

MALAYSIAN ASSOCIATION OF PAEDIATRIC PALLIATIVE CARE

JUNE 2020



在一个凌晨的3点，我给B做第三次的心肺复苏。他的父母正坐在远处角落里的长凳上，有好几次想窥视围帘里所发生的事。围帘里的正全力奋战抢救，而他们却被隔离开来，在围帘之外。

B是一个10个月大、患有主动脉瓣膜闭锁不全的男孩。一场败血病加剧了他的病情，因此在小儿心脏病重症监护病房里接受治疗。当天早上，我和心脏科顾问医生给他做了心脏超音波检查他的心脏功能。透过屏幕，只见少量的血泵到全身，其余的却都回流到心脏里。我们知道即便给他注射再多的心肌收缩力增强剂也无法延缓他的心脏衰竭。

我们以沉重的心地将这消息告诉孩子的父母。在接下来的讨论中，我们向父母解释B的病情非常不乐观，并询问是否要给B做心肺复苏术的急救措施。毫无意外地，父母都同意了。我们实在不忍心告诉他们其实抢救不会带来任何的改变。

晚上10点，我被告知B的心脏骤停。心肺复苏术随即进行，并给他注射了肾上腺素。B于是恢复了心跳，而父母似乎见到了零星的希望。至于我已经做好迎接漫漫长夜的准备了。午夜一点，令人恐惧的时刻如预期般降临了。这一次，我们进行更长时间的心肺复苏术，同时也注射更高剂量的肾上腺素。父母的眼神中透露出了疑惑。在这个节骨眼上，我实在不知道该对他们说些什么，于是选择保持缄默。

凌晨3点20分。依旧坐在长凳上的父母，显得多么地无助而忧虑。我盯着B胸前大块的淤青，反复的胸腔按压已使得淤青中心的皮肤微微撕裂。我都做了什么？这样的急救，除了给B带来伤害以外是否有丝毫益处？此刻陪伴在孩子身边的，应该是父母而不是我。我向父母走去并告诉他们这残酷的事实——心肺复苏术已无法扭转孩子的情况，B需要的是父母陪伴在侧，而不是我。

这一次，换我坐在长凳上，而父母守在B的床边。妈妈哭泣着，爸爸环抱着妈妈的肩膀，无声的眼泪却也径自滑落胸前。而后，妈妈向B道歉，让他出生时就有心脏缺陷，还无法帮助他脱离生命危险。我多么想告诉她这不是她的错，但我也知道这是属于他们的私人时刻。渐渐地，妈妈冷静下来并开始给孩子哼唱儿歌。在面对如此悲痛结局的当下，如此的亲密时刻弥足而珍贵！我猜想这一定是他们平常生活里的欢乐时光。他们眼里的悲楚逐渐消散，取而代之的，是充满对孩子满满的爱意。

凌晨四点，B在充满爱意的怀里及妈妈慈爱的歌声中回到天堂去了。破晓时分，在一切手续办妥后，他们准备离开加护病房。离开前，妈妈告诉我他们已经选好了一个足以容纳两个大人和一个小孩的墓地，那一天的到来将是他们一家团圆的日子。从悲痛中痊愈是一条漫漫长路，但我知道他们已走在这条路上了。

这是发生于五年前的事，但我还常常想起他。虽然那是极其艰难的对话，但是就在那一天我明白了，带着悲心、同理心及坦诚的对话，能同时给家属和医生带来痊愈。



陈如洧儿科医生。MBBS(IMU), MRCPCH (UK), PEDIATRICS BIOETHICS (US).  
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陈医生现为哥伦比亚亚洲医院儿科专科医生。他也致力于推广儿科临终关怀与儿科生物伦理学的相关知识。



## Angel Child/Youth Card Project



P.P.C. Annual Workshop 2021

Volunteer Training Program



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

Swiss Garden Hotel, Bukit Bintang, Kuala Lumpur

24<sup>th</sup> to 26<sup>th</sup> March 2021

Supporting from the beginning



Contact us if you wish to participate in our activities.



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MAPPAC

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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](http://www.mappac.org))
  - Forums/Meetings
  - Speeches
- 2) Media - Radio interview/TV show / Newspaper reports
- 3) Parental Information
  - Leaflet / Booklet



## 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 multi-disciplinary 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**  
It begins when the illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- ◆ **Places of Care**  
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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