

NEWSLETTER

Issue No: 07

MALAYSIAN ASSOCIATION OF PAEDIATRIC PALLIATIVE CARE

JULY 2020



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

Utilising the Power of the Mind

Hypnotherapy in Pediatric Palliative Care

Issue No: 07/007

MALAYSIAN ASSOCIATION OF PAEDIATRIC PALLIATIVE CARE

JULY 2020



The pain has become your constant companion, and with each passing day, it increases in intensity with no end in sight. Relief only comes when you fall asleep and that is becoming even harder to come by. Mentally exhausted, life loses the sparkle. Food taste bland, it could be from the medication or from the anxiety of not knowing how to cope with your current situation. Even if food is managed to be ingested, keeping it down long enough for the body to absorb any nutrients from it is another challenge.

However, there is the occasion relief when something exciting happens and in that brief moment, the pain is forgotten and all focus is on the current event. Depending on such an event to happen is like throwing a rock into the ocean and expecting to hit a fish as it sinks to the bottom. Is there a way to create this event at will?

The power of the mind is an incredible thing. Weighing about 3 lbs, our brain is not the biggest organ in our body but is a powerful organ that is capable of many incredible feats. The realm of the subconscious holds potentials that has yet to be discovered. We have all experience daydreaming, when our mind takes us to these magical place where all our worries are non-existence at least during that moment of daydreaming.

Enter hypnosis, a method of allowing the subconscious mind to come forward while the conscious takes a backseat. Contrary to popular belief, hypnosis is not sleep where the hypnotist have full control and dig the deepest secrets from the one under hypnosis.

Does hypnotherapy have a role in palliative care? Hypnotherapy is like a guided tour where the hypnotherapist guides the subject to explore his or her world and to focus on the area that will be beneficial to the subject. In many instances a trained hypnotherapist will guide the patient to help them see their situation in a different perspective. Every moment spent on quality living is a moment to be cherished. The inevitable can't be avoided but by providing them with the skills to help them cope with their current situation

will give them back their sense of control. Hypnotherapist will give post-suggestions and allowing the patient to carry out self-hypnosis after the session.

Pain is a common complaint and the common side effect of prolonged pain includes stress and anxiety. The sensation of pain can even be amplified by the stress level. Hypnotherapy aims to manage the fear and anxiety relating to the pain by helping the patient focus on relaxation and letting go of distracting thoughts. During the altered consciousness state, suggestions are given to encourage pain relief. Hypnotherapist will give post-suggestions and allowing the patient to carry out self-hypnosis after the session.

In a recent case, a patient with Relapsed Acute Lymphoblastic Leukemia was introduced to us and his wish was to experience a fishing adventure. Upon meeting him and after a brief introduction, I began to talk to him about the trip and the activities we have planned for him. His excitement was unmistakable and he began to talk about his fishing expe-

rience. The shy boy that we met a few moments ago transformed into an energetic young man ready for adventure.

After a short briefing, the fishing commenced. He insisted on using his own tackle and we promptly set it



up for him. Within a few moments, he was on to his first fish. As the fish pulled the line out of the screaming reel, he expertly controlled the rod to keep the fish under control. Unfortunately the line snapped and the fish was lost. I was expecting the dark clouds of disappointment to blow over him but with determination, he said, "Let's try again."

Moments later, he was on to another fish and judging from the pull, this was a better fish and he calmly "battle" the fish. It was a strong fish but he did not give up despite the long fight. Finally a 4 kg. Patin was landed and he proudly posed with the fish for a quick photo. It was time for lunch.

We know some patients would have difficulty eating and keeping the food down. We were amazed to watch him eat happily while chatting with our team members. The late morning sun was hot but he was determined to catch his next fish. Soon, he was fighting another fish. Then another fish in quick succession. We were worried that he would be tired from the exertion and the blazing sun but he was still going strong.

Later, he asked for food and we gladly ordered an instant cup noodle and a drink for him. He hungrily ate the food and went back to fishing. We were surprised by his determination and energy. Not once did he complain about the heat or the exhaustion. If we didn't know about his condition, we would have assumed that he was a normal healthy young teenager.

At the end of the trip, we asked if he would like to come fishing with us again and he answered "Yes" without missing a beat. I asked him when he would like to fish again and he said "This weekend!"



During the entire trip, we were all giving him suggestions about how he could control the fish, overcame the difficulties and that he could always look at the photos and videos of the trip to improve his fishing skills.

The power of the mind is indeed amazing. When one is focused on the things that makes them happy or excited, the pain or discomfort can be temporarily set aside, giving the patient the quality of life that they deserve. Every minute of quality living gained, is a minute of quality life achieved.



This article is contributed by Mr. Brandon Ho
CMT, IACT (USA), Certified Clinical Hypnotherapist ACHE (USA)

Brandon Ho founded Ultimate Training Sdn Bhd and Ultimate Performers Sdn Bhd. He specialises in personal development and language training. He formulates and conducts programmes for working adults as well as students. His clients come from diverse backgrounds and countries. Using concepts of NLP and Hypnotherapy, Brandon has created high-impact programmes that not only educate the participants but also to inspire them to be the best that they can be. Brandon is a Practising Member of AHPM (Association of Hypnotherapy Practitioners, Malaysia), the peak body for hypno-therapist and other mind science practitioner in Malaysia. He also conducts training workshops in his centres in Sunway and Dataran Mentari.

Brandon Ho will be sharing on **Hypnotherapy for Pain Management**.

How Far to Persist and When To Withdraw?

Issue No: 07/008

MALAYSIAN ASSOCIATION OF PAEDIATRIC PALLIATIVE CARE

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UP was born with sacral agenesis secondary to maternal diabetes mellitus and associated abnormalities of neurogenic bladder, coarctation of aorta with abnormal aortic and mitral valves. Due to factors of poor socio-economic background and residing in a rural district, parents of UP chronically defaulted despite social welfare aid.

She had an episode of urosepsis and acute kidney injury at 3 years of age where clean intermittent catheterization was introduced. She defaulted and only represented at 7 years of age in end stage renal failure (ESRF)

with severe uremic encephalopathy. During family conference, conservative therapy was broached as child was severely malnourished (body weight of 8kg), had severe contractures and was totally dependent with GMFCS 5. Due to the mother's bad obstetric history, and being the only girl in the family with another older brother, parents have earnestly requested for trial of dialysis.

She was started on continuous ambulatory peritoneal dialysis (CAPD). Post dialysis UP improved and was able to attend to ADL activities with the use of a wheelchair. However she developed fulminant peritonitis after 2 years, resulting in cessation of CAPD.

After consulting with the paediatric cardiologist, he was of the opinion that haemodialysis (HD) was not contraindicated as she still had good ejection fraction on car-

diac evaluation. At that point in time due to the stress of looking after UP and family financial problem, the mother ran away from home. We discussed the option of not proceeding further with conversion to chronic haemodialysis as the father being a single parent was unable to cope with her care that included sending her for 3x/ week haemodialysis sessions. How ever, the father was very persistent in proceeding with therapy. As the father was staying in the rural area and UP needed to be dialysed in a haemodialysis (HD) centre that was able to dialyse young children, a kind NGO provided her a place to stay in a welfare home and they will undertake the travel arrangements for the HD sessions.

UP was happy staying in the home with good interaction with other home tenants and caregivers for

6 years and highly functional-
ly with mobility assisted by
wheelchair. She also partici-
pated happily in all our hospi-
tal organised PPC activities.
The mother who ran away
from home also developed
ESRF, was dialysed in the
same HD unit as UP and sub-
sequently died due to compli-
cations.

At the age of 15
years old, she developed
pulmonary oedema requiring
mechanical ventilation and
leading to an acute life threa-
tening event that resulted in
hypoxic encephalopathy. She
subsequently was extubated,
however, with tracheostomy
and tube feeding and was
totally dependent. A frank
discussion was held with the
father regarding the futility of
persisting with HD sessions
and continuing on will not be
in the best interest of the
child. Subsequently haemodi-
alysis sessions was withheld

and the patient passed away
2 weeks after cessation of
dialysis therapy.

Learning points:

1. UP illustrates a patient with multiple comorbidities where palliative care conversation was initiated early and reiterated during every health crisis. Although poor prognosis at the start, yet with appropriate therapy she was rehabilitated and enjoyed 8 years of reasonable quality of life despite that there was concomitant family and social factors that made her care challenging.
2. The well-being of parents is essential to the well-being of children with life-limiting illness. Parents are vulnerable to a range of negative financial, physical, and psychosocial issues due to care-giving

tasks and other stressors related to the illness of their child. Paediatric palliative care team need to support these parents in decision-making and difficult conversations, by managing pain and other symptoms in the ill child, addressing parent and family needs for care coordination, respite, bereavement, social and emotional support.



This article is contributed by Dr. Susan Pee who is currently practicing as a paediatric nephrologist in Hospital Sultan Ismail Johor Bahru. She graduated with a Bachelor of Medicine & Bachelor of Surgery from University Malaya and later obtained her Membership of the Royal College of Paediatrician United Kingdom. She is a MRCPCH examiner for Malaysia circuit after obtaining her FRCPCH. She is one of the authors for paediatric nephrology chapters in the 4th Edition of the Malaysian Renal Replacement Therapy CPG as well as the 4th Edition of Paediatric Protocols for Malaysian. She was involved in the setting up of the paediatric palliative care unit in Hospital Sultan Ismail in 2013.



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

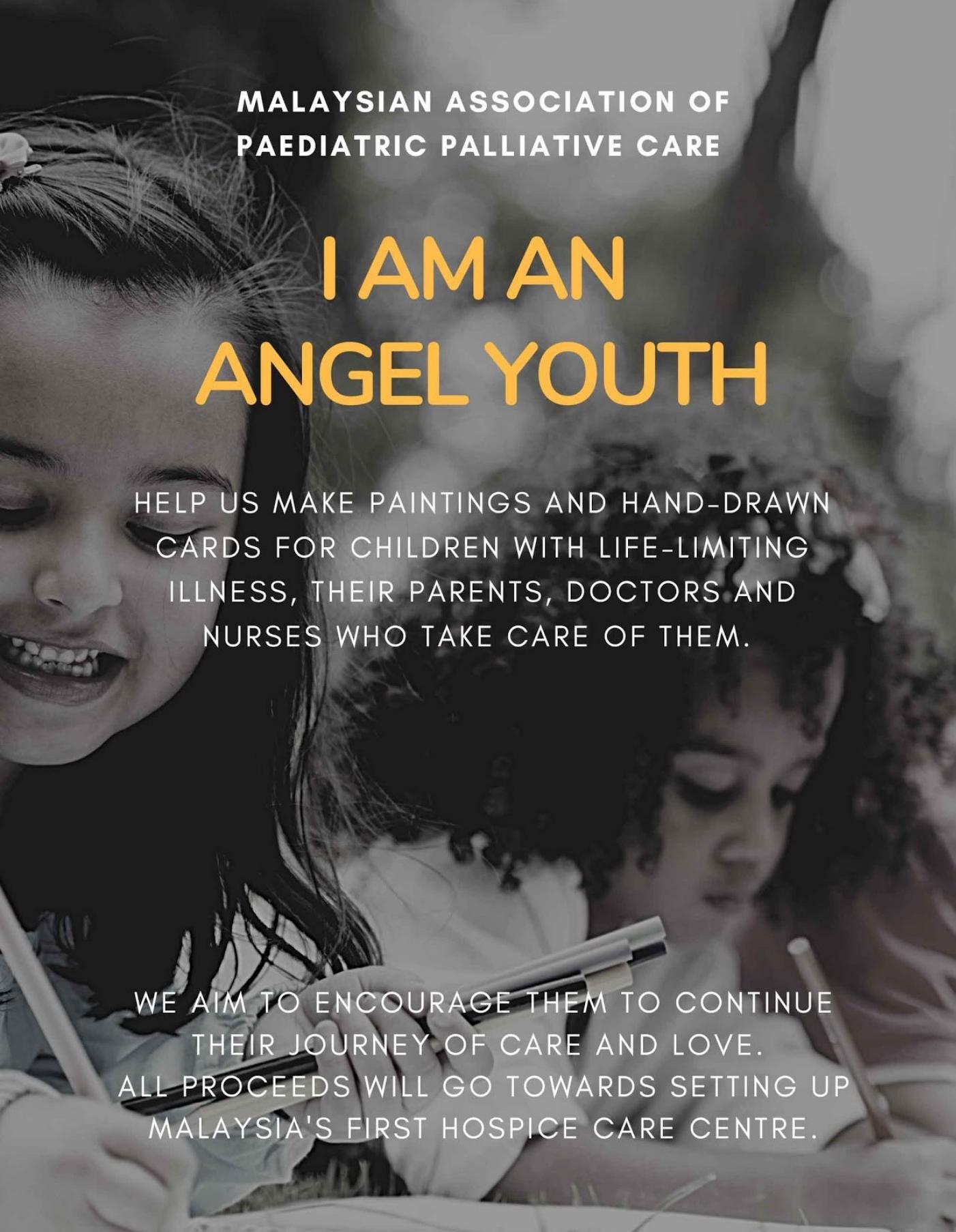
Calling for children and youths to hand draw paintings and cards for:

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 | 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 | 0162231357

Mengguna kuasa otak dan Hipnoterapi dalam Perawatan Paliatif kanak-kanak

Isu No: 07/007

MALAYSIAN ASSOCIATION OF PAEDIATRIC PALLIATIVE CARE

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Kesakitan menjadi peneman bersama, dikala setiap hari yang berlalu, ianya meningkat hingga ketiadaan penghujung. Kerehatan hanya datang bila dia terlelap dan ianya seakan menjadi semakin sukar. Bila keletihan mental berlaku, hidup seolah hilang seri. Makanan dirasakan hambar, mungkin dari kesan sampingan ubat ubatan atau keresahan kerana tidak mengetahui bagaimana cara untuk mengatasi situasi ini. Jikalau makanan itu dapat dihadam, ianya menjadi satu cabaran untuk memastikan makanan itu berada di dalam badan sebelum dihadamkan semua.

Walaubagaimana pun, ada masa pesakit merasa sedikit lega apabila sesuatu yang menarik berlaku. Dalam masa yang singkat, sesuatu kesakitan itu dapat dilupakan dan semua tumpuan diberikan pada keadaan terkini. Bergantung pada sesuatu peristiwa, ianya seperti melemparkan batu ke laut dan mengharapkan agar ia nya akan dapat mengena seekor ikan setelah ianya tenggelam ke dasar. Adakah kita boleh berbuat sebegini seperti dengan apa yang dikehendaki?

Kuasa otak merupakan sesuatu yang menakjubkan. dengan seberat 3 pounds, otak kita bukanlah organ yang besar di dalam badan kita tetapi mempunyai keupayaan dari pelbagai sudut. Bila kita berada di alam separa sedar, ia mempunyai potensi yang belum di temui. Kita semua mempunyai pengalaman tentang lamunan, bilamana otak kita mengembara di tempat

magikal dimana segala kebimbangan tidak berlaku, sekurang kurangnya semasa lamunan tersebut.

Hipnosis, merupakan sesuatu metod yang membolehkan otak menjadi separa sedar, dan kesedaran kita tersembunyi. Berbeza dengan kepercayaan popular, hipnosis bukannya merupakan proses dimana seseorang itu tidur dan hipnoterapis mempunyai kawalan dan mencari rahsia daripada seseorang.

Adakah hipnoterapi mempunyai peranan dan bidang perawatan paliatif kanak-kanak? Hipnoterapi merupakan teknik dimana hipnoterapist akan memandu seseorang mengenapasti dunia mereka dan membolehkan mereka fokus kepada apa yang berfaedah untuk mereka. Contohnya, hipnoterapis akan membawa pesakit untuk melihat keadaan mereka dalam perspektif yang berbeza. Setiap detik yang

digunakan untuk kualiti kehidupan ialah merupakan detik yang wajar di hargai. Apa yang akan berlaku mungkin tidak dapat dilakukan tetapi dengan memberi keupayaan skil untuk mengatasi dengan keadaan semasa yang akan membolehkan mereka untuk mengawal keadaan.

Kesakitan merupakan keluhan yang biasa dan kesan sampingan biasanya dari-pada kesakitan yang berpanjangan termasuk tekanan dan keresahan. Perasaan sakit itu boleh dikuatkan dengan tingkatan stres yang tinggi. Hipnoterapi bertujuan untuk mengurus ketakutan dan keresahan berkait dengan kesakitan dengan membantu pesakit untuk memfokus pada kerehatan dan melepaskan dari kekusutan pemikiran.

Semasa keadaan separa sedar, cadangan akan diberikan untuk mengurangkan kesakitan. Hipnoterapist akan memberikan cadangan selepas terapi dan membiarkan pesakit menjalani hipnosis kendiri selepas sesi itu berakhir.

Dalam satu kes, seorang pesakit akut limfoblastik leukaemia berulang telah dikenalkan kepada kami dan kehendak beliau adalah untuk mencari pengalaman memancing. Seusai berjumpa dengan dengan beliau, dan setelah pengenalan ringkas, saya mula bercakap dengan beliau tentang perjalanan dan aktiviti yang dicadangkan oleh beliau. Beliau begitu gembira dan mula bercakap mengenai kehendak beliau untuk mendapat pengalaman me-



mancing. Kanak kanak yang pemalu yang kita temui pada mulanya itu berubah menjadi seorang yang bertenaga dan bersedia untuk mencapai kehendaknya.

Selepas percakapan yang singkat, kita memulakan aktiviti memancing. Beliau ingin menggunakan alatan memancingnya dan kami menolong untuk menyiapkan baginya. Dalam beberapa saat, beliau mendapat ikan pertamanya. Semasa ikan itu ditarik, beliau mengawal

jorannya untuk memastikan ikan dibawah kawalannya. Dengan tidak semena mena, tali joran itu terputus menyebabkan ikan itu terlepas. Saya merasakan bahawa beliau akan merasa kecawa tetapi kehendak beliau mendorongnya untuk mencuba sekali lagi.

Beberapa ketika, dia mendapat seekor lagi ikan dan daripada tarikan tersebut, kami merasakan ikan itu yang lebih baik, dan beliau secara tenang 'berperang' dengan ikan tersebut. Kali ini beliau mendapat ikan yang kuat dan beliau tidak cepat berputus asa walaupun terpaksa berperang dengan agak lama. Akhirnya, ikan patin seberat 4 kg berjaya di tarik dan beliau begitu bangganya bergambar dengan tangkpanya. Lanya masa untuk makan tengahari.

Kami memahami pesakit begini mungkin akan mengalami kesukaran untuk makan dan memastikan makanan itu berada dalam perutnya. Kami kagum melihat beliau menikmati makanan sambil berbual dengan kami. Di akhir pagi, dimana matahari tidak terlalu

panas tetapi beliau tetap ingin lagi mencuba untuk mendapatkan ikan lagi. Selepas itu beliau mendapat seekor lagi. Kemudian seekor lagi. Kami bimbang jika beliau akan mengalami keletihan kerana penggunaan tenaga yang banyak dan keadaan panas di bawah matahari yang terik, tetapi beliau tetap bersemangat.

Kemudian, beliau meminta makanan dan kami gembira memberikannya secawan mee dan minuman. Beliau memakan makanan tersebut kerana kelaparan dan kemudian kembali memancing. Kami amat terkejut dengan keupayaan dan tenaga beliau. Beliau tidak memberi rungutan tentang kepanasan atau keletihan.

Jika kami tidak tahu masalahnya, kami mungkin menganggap beliau adalah anak muda yang normal.



Pada akhir perjalanan tersebut, kami bertanya beliau jika beliau mahu kembali memancing bersama kami dan beliau menjawab secara spontan sebagai "Ya" tanpa kehilangan suara. Saya juga bertanya kembali bila beliau ingin kembali memancing dan jawannya "*minggu ini*".

Semasa perjalanan itu, kami memberikan saranan tentang cara mengawal ikan, mengatasi masalah beliau dan membenarkan beliau boleh melihat foto dan video tentang perjalanan untuk membantu beliau seperti memperbaiki skil memancing beliau.

Kuasa otak kita adalah sesuatu yang menakjubkan. Bila seseorang itu dapat memfokuskan pada sesuatu yang mengembirakan mereka, kesakitan dan rasa tidak selesa itu hilang, dan ianya memberikan pesakit itu kualiti kehidupan yang lebih baik. Setiap minit kualiti hidup yang diperolehi, ianya merupakan seminit kualiti kehidupan yang dicapai.



Artikel ini disumbangkan oleh Brandon Ho CMT, IAT (USA), Hipnoterapist Klinikal (USA)

Brandon Ho merupakan seorang pengasas Ultimate Training Sdn Bhd dan Ultimate Performers Sdn Bhd. Beliau menjurus dalam bidang perkembangan kendiri dan latihan bahasa. Beliau memulakan dan menjalankan program untuk orang dewasa yang sudah bekerja dan pelajar. Klien beliau berasal dari pelbagai latar belakang dan negara. Menggunakan konsep NLP dan hipnoterapi, Brandon telah berjaya mencipta program yang berimpak tinggi yang bukan sahaja menolong peserta dan meningkatkan kebolehan mereka. Beliau merupakan ahli APHM dan hipnoterapist serta pakar sains minda. Beliau juga memulakan latihan 'workshop' di Sunway dan Dataran Mentari. Beliau akan menceritakan topik - Penggunaan Hipnoterapi untuk rawatan kesakitan.

Sejauh mana kita perlu pergi dan bila untuk berhenti?

Isu No: 07/008

MALAYSIAN ASSOCIATION OF PAEDIATRIC PALLIATIVE CARE

JULAI 2020



UP dilahirkan dengan diagnosis 'sacral agenesis' akibat penyakit diabetes mellitus ibunya dan melibatkan masalah pundi kencing neurogenik, masalah jantung coartation aorta bersama masalah di injap aortik dan mitral. Disebabkan faktor ekonomi yang tidak baik dan keluarga tinggal di kawasan kampung, ibubapa UP tidak membawa UP untuk rawatan susulan walaupun setelah diberi bantuan kebajikan.

UP mendapat satu episod jangkitan kuman di buah pinggang mengakibatkan kegagalan buah pinggang akut

pada umur 3 tahun dimana kateterisasi berkala diperkenalkan padanya. Dia menghilangkan diri dari rawatan susulan selepas itu dan datang semula pada umur 7 tahun dengan masalah kegagalan buah pinggang tahap akhir dengan masalah ensefalopati uremia. Semasa perbincangan bersama keluarga, rawatan konservatif dicadangkan kerana pesakit tersebut kekurangan berat (berat badan 8kg), mempunyai kontraktur sendi yang teruk serta bergantung penuh kepada penjaga dengan GMFCS 5. Kerana masalah ibu semasa mengandung dan dia merupakan anak perempuan yang seorang sahaja dalam keluarga bersama seorang abang, keluarga memohon agar UP diberi peluang untuk mendapatkan rawatan dialisis.

UP memulakan dengan dialisis peritoneal (CAPD).

Sesudah dialisis, UP menjadi lebih baik dan berupaya menghadiri aktiviti ADL dengan kerusi roda. Walau bagaimana pun, dia mendapat peritonitis fulminan selepas 2 tahun menyebabkan terhenti CAPD.

Selepas perbincangan bersama pakar kardiologi kanak kanak, beliau berpendapat bahawa HD tidak mempunyai apa apa kontraindikasi kerana UP mempunyai fungsi jantung yang baik selepas evaluasi kardiologi. Pada masa tersebut, kerana stres menjaga UP dan masalah kewangan keluarga, ibu nya mlarikan diri daripada rumah. Kita berbincang tentang opsyen untuk tidak teruskan dengan menukar dialisi kronik kerana ayahnya yang berseorangan dan tidak berupaya mengatasi dengan masalah anaknya termasuk menghantar UP untuk hemo-

dialysis sebanyak 3x seminggu, tetapi ayahnya berkeras untuk meneruskan terapi tersebut. Kerana ayahnya tinggal di kawasan kampung dan keperluan UP untuk mendapatkan rawatan hemodialisis yang berupaya membuatnya, satu badan NGO telah menyediakan tempat tinggal dan mereka akan menyelesaikan tentang masalah pengangkutan untuk sesi HD.

UP sangat gembira tinggal di rumah tersebut dan mempunyai hubungan rapat dengan penghuni dan penjaga rumah tersebut selama 6 tahun, sehingga dia mempunyai fungsi dan kebolehan bergerak menggunakan kerusi roda. Dia juga terlibat secara aktif dengan aktiviti yang dilaksanakan oleh pasukan PPC. Ibunya yang melarikan diri dari rumah juga mempunyai kegagalan buah pinggang yang terminal dan dirawat bersama dengan UP, kemudian meninggal akibat komplikasi.

Pada umur 15 tahun, dia mengalami paru-paru berair dan akibatnya memerlukan mesin pernafasan, kemudian disusuli mendapat episod akut life threatening yang mengakibatkan dia mendapat ensefalopati akibat kekurangan oksigen. Dia perlu di intubasi, kemudian dibuat tracheostomi, salur pemakanan dan bergantung penjagaan sepenuhnya. Selepas perbincangan lanjut bersama ayahnya berkaitan futiliti rawatan HD dan perpanjangan HD tersebut mungkin bukan menjadi kepentingan bagi UP lagi. Sesi HD dihentikan dan dia meninggal dunia 2 (dua) tahun selepas pemberhentian terapi tersebut.

Pembelajaran:

1) UP menunjukkan kesihatan yang baik walaupun terdapat pelbagai komorbiditi di mana diskusi paliatif dimulakan dan diberitahu setiap krisis. Walaupun, prognosis itu agak teruk, dengan rawatan yang betul, dia melalui rehabilitasi

dan berupaya hidup selama 8 tahun dengan kualiti kehidupan yang setimpal walau pun ada faktor keluarga dan sosial yang menyebabkan rawatan sampingan yang sukar.

2) Keadaan ibubapa adalah penting untuk kebaikan abak anak yang mempunyai penyakit kurang jangka hayat. Ibubapa terdedah kepada banyak masalah seperti kewangan, fizikal, psikososial kerana rancangan penjagaan dan apa-apa tekanan lain berkaitan dengan penyakit anak-anak tersebut.

Pasukan rawatan paliatif kanak-kanak memerlukan sokongan untuk ibubapa membuat keputusan dan mendengar perbualan yang sukar, dengan mengambil kira kesakitan, symptom lain pada kanak-kanak yang sakit, dan menyediakan perbincangan dengan ibu-bapa dan keluarga tentang keperluan meraka seperti koordinasi rawatan, respite, bereavement social dan emosi.

Artikel ini disumbangkan oleh Dr. Susan Pee

Beliau merupakan pakar kanak-kanak bahagian nefrologi yang bekerja di Hospital Sultan Ismail Johor Bahru. Beliau lulus MBBS dari Universiti Malaysia dan kemudian mendapat membership daripada Royal College of Paediatrics and Child Health UK. Beliau merupakan pemeriksa MRCPCH untuk circuit Malaysia selepas mendapatkan FRCPCH. Dia juga merupakan salah seorang pengarang buku nefrologi bab 4th Edition di Malaysia, mengenai rawatan gantian renal CPG dan juga 4th edisi PP di Malaysia. Beliau juga terbabit sama dalam penyediaan PPC di Hospital Sultan Ismail pada tahun 2013.



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



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

Dr Sujatha Doraimanickam
Creative drama intervention



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LOVED CAFE
LEARNING ON VOICING
EMOTIONS OF DEATH

LOVED CAFE

Welcome to a conducive place to hang out and talk about grief, loss, and other complex family stories - minus the complexity.

Saturday 24th October 2020,
from 2pm - 5pm,
Yuan Hui Educare Centre, PJ

LOVED stands for Learning on Voicing Emotions of Death



ADULT CAFE SESSIONS

Join our LOVED Cafe Sessions with a Twist - where families can participate in a facilitated group discussion about both hypothetical and experiential death, fear, grief and loss in a safe and secured way through various group activities and sharing. Every session is limited to 10 adults.

CHILDREN SESSIONS

Loss and bereavement can be hard for children to articulate. In these sessions, children get to engage in group play, storytelling, and exploring their thoughts and feelings with our registered therapist or ~~pediatric~~ doctor. Every session is limited to children aged 12-18 years.

WHY DISCUSS GRIEF?

Children and adults confront grief, loss and death differently, and need a space where thoughts and feelings can be both validated and unconditionally accepted. Acceptance of our emotions as well as the feeling of 'being seen', can help us make better meaning of our own experiences.

INQUIRIES/CONTACT US

For more information or to register please contact
Jacqueline: 016-2231357

Location: Yuan Hui Educare Centre
2, Jalan BU6/7, Bandar Utama,
47800 Petaling Jaya

LOVED CAFE IS RUN BY MAFAC (Malaysian Association of Facilitators Facilitate) and committed to providing total care to all children and family who are facing the life-limiting illness.

We Believe In..

creating spaces that enable open sharing, healing and unconditional community acceptance

MAFAC

善用大脑的力量

催眠疗法与儿童安宁疗护

Issue No: 07/007

MALAYSIAN ASSOCIATION OF PAEDIATRIC PALLIATIVE CARE

JULY 2020



疼痛感如影随形。日子一天天地过，痛觉不断地增加，而且无边也无际。

只有当你入睡时疼痛才会稍作缓解，但这也逐渐变得不容易了。精神疲惫，生命失去了光彩。或许是因为药物，又或者是对于当前的状况手足无措而引起的焦虑，让你食之无味。即使把食物吞咽下去，能不能从中吸取养分那也是另一个挑战。

尽管如此，当一些令人兴奋激动的事情发生时，这样的情况会有所缓解。在那一瞬间暂时忘却了痛苦，所有的注意力都集中在当前的事件上。寄望于此类的事件发生，就犹如往大海里投入一块石头，并期待石头在沉入海底时击中一条鱼。究竟有怎样的方法能按照自我的意愿使其发生呢？

大脑的力量非常不可思议。它约3磅重，虽然不是人体中最大的器官，但却拥有许多强大的功能。尤其潜意识的潜力尚待发觉。我们都曾经做过白日梦，在那时空里，任由思绪带领着我们穿越无忧无虑的奇幻世界。

进入催眠状态，潜意识作用上升，意识退居幕后。有别于普遍的看法，催眠不等于使人进入睡眠状态，反之，催眠治疗师能完全控制并挖掘被催眠者埋在最深处的秘密。

催眠疗法在安宁疗护中扮演着什么样的角色？催眠疗法就像是一名向导，引领着被催眠者探索自己的内在世界，并从中获得益处。专业的催眠治疗师会引导患者从不同的角度看待自己的处境。每一个优质生活的当下都是值得珍惜的。即便病情无法逆转，催眠治疗依然能够帮助患者于当前的情况中重新获得对生活的掌控权。

患者最常见的投诉是疼痛。慢性疼痛会导致压力及焦虑的副作用。压力水平甚至能放大疼痛感。催眠疗法主要帮助患者控制因疼痛所带来的恐惧及焦虑感，并专注于放松及消除混杂的思想。因催眠而产生的意识的改变状态中，治疗师会提出意见以促进疼痛的缓解。而后治疗师也会建议，让患者能够在疗程后进行自我催眠。

在最近的案例中，有一名患有复发性急性淋巴细胞白血病患者转介到我们这里。他希望能体验一次钓鱼的冒险之旅。与他会面时我给他做了简短介绍，并且与他谈了这次的旅程及为他计划的活动。他显然非常的兴奋激动，还开始谈论他的钓鱼经历。这在不久前还羞涩的男孩突然充满活力，整装待发去冒险。



简短介绍后，钓鱼之旅开始了。他坚持使用自己的钓饵，而我们也刻不容缓地为他预备。不出一会儿，第一条鱼上钩了。当上钩的鱼将鱼线轮的线拉出时，他手法熟练地控制住钓竿及上钩的鱼。不幸的是钓线断线，让鱼儿游走了。我原来估计他会因此而失望不已，但是他却充满毅力地说：“再试一次吧！”。

稍作片刻，另一条鱼上钩了。从拉力来看，这是一条更好的鱼。他从容地与那条鱼“搏斗”。那鱼力大劲猛。但即便经历长时间的搏斗，他仍旧不愿放弃，终于，一条4公斤的巴丁鱼上钩了。他骄傲地与那条鱼快速合影。那时已是午饭时间。

有些患者有进食及进食后呕吐的困难。看着他开心地进食和我们的队员聊天，我们纷纷感到惊讶。中午时分，阳光炙热，他仍坚持要再钓一条鱼。很快地，他又陷入了另一次的搏斗，紧接着再来一场。我们担心他会因为费力和炙热的阳光而感觉疲累，但他看起来还是那么地精力旺盛。

之后，他要求吃点东西。我们很高兴地为他点了一份方便面和饮料。他狼吞虎咽地把它们吃了，然后又钓鱼去了。他的毅力和精力让我们感到非常的惊讶。炎热的天气并没影响他钓鱼的兴趣，也没听他说起感到疲惫。如果不是事先就知道了他的身体状况，我们会以为他是一个正常健康的少年。



旅程结束时，我们询问他是否愿意再一起钓鱼，他毫不思索地回答：“当然”。我问他什么时候想再钓鱼，他说：“这周末！”。

在整个旅程中，我们向他提出各种有关如何控制鱼、克服难题的建议，让他能够随时通过查看旅程中的照片和视频提高捕鱼的技能。

大脑确实有惊人的力量。当一个人专注于使他们感到快乐或兴奋的事物时，就能暂时忘却疼痛或不适感，让患者享有应有的生活质量。每一分钟良好的生活质量，意味着一分钟生活质量的实现。



Brandon Ho CMT, IACT (USA), Certified Clinical Hypnotherapist ACHE (USA)

Brandon Ho 创办了Ultimate Training Sdn Bhd and Ultimate Performers Sdn Bhd。他的专业领域是个人发展及语言培训，为在职成年人及学生制定课程并进行培训。他的客户来自不同的背景及国家。他运用NLP及催眠疗法的概念，创建了具有高影响力的课程，教育参与者的同时，更激发他们成为更好的自己。**Brandon**是AHPM（马来西亚催眠治疗师协会）的执业会员。AHPM是集合了马来西亚催眠治疗师和其他心智科学从业者的主要机构。他还在其位于Sunway 及 Dataran Mentari 的中心提供培训。

要坚持多久与何时放弃？

Issue No: 07/008

MALAYSIAN ASSOCIATION OF PAEDIATRIC PALLIATIVE CARE

JULY 2020



UP天生患有继发于母体糖尿病的骨发育不全，并伴有神经性膀胱异常，主动脉缩窄以及主动脉瓣和二尖瓣异常。由于社会经济背景差，且居住在农村地区，UP的父母尽管获得了社会福利援助，经济状况依然极度窘迫。

UP在三岁时尿毒症发作和出现急性肾损伤，因此采用了干净的间歇性导尿治疗法。遗憾的是治疗并不成功，UP在七岁时被诊断为末期肾衰竭，并同时患有尿毒症性脑病。由于UP严重营养不良（体重仅八公斤），又患有严重挛缩及行动需完全依赖他人（属于粗大功能分类系统第五级，Gross Motor Function Classification System Level V），家人在谨慎商讨后决定采取保守疗法。基于母亲不良的产科史，又因是家中只有一名兄长的独女，UP的父母诚恳地要求进行透析治疗。

UP开始了连续性可携带腹膜透析（Continuous Ambulatory Peritoneal Dialysis，简称CAPD）。接受透析治疗后的UP身体情况获得改善，并且在轮椅的辅助下能进行日常生活活动。但UP在两年后不幸的发展为爆发性腹膜炎，因而被迫终止腹膜透析。

在咨询了儿科心脏科医生后，基于UP在心脏评估中仍具有良好的射血分数，医生认为血液透析不会给UP造成负面影响。在那个时候，UP的母亲在面对照顾UP与家庭经济问题的压力下选择离家出走。由于顾虑UP的单亲父亲无法应付UP的护理（这其中包括接送UP进行每周三次的血液透析），医生曾与UP的父亲讨论了不让UP转换成慢性血液透析的可行性。虽然如此，UP的父亲始终坚持治疗。由于父亲居住在农村地区，而UP必需到能为儿童进行血液透析的中心接受治疗，一个热心的非政府组织为UP在福利院提供了住宿，并且还负责安排接送UP往返血液透析中心。

在福利院的六年中，UP是快乐的。她与住在福利院的其他人和看护人员有着良好的互动，且在轮椅的辅助下拥有良好的活动能力。（PPC = Pediatric Prehospital Care?）UP离家出走的母亲也因末期肾衰竭而在同一个中心接受血液透析的治疗，而后因并发症而病逝。

UP在15岁时出现了肺水肿而需要依赖呼吸器协助换气，还出现了危及生命的急性健康状况，进而导致脑缺氧。她随后被拔管，但由于进行了气管切开术和需要管饲，UP变得完全不能自理。在和UP的父亲坦诚地讨论了对于继续血液透析治疗的成效后，决定了那并不会对UP带来最佳的益处，而后停止了血液透析的治疗。 UP在两周后离开了。

学习观点：

- 1) UP是一名患有多种合并症的患者，有关给她实施安宁疗护的对话进行得早，并在每次出现健康危机中重复进行对话。尽管开始时预后（预测疾病的可能结果）做得不够好，但经过适当的治疗，即便在家庭和社会因素的影响和挑战下，她逐渐康复并享有8年有质量的生活。

- 1) 父母的心理健康对患有末期病症的孩子的心理健康起着至关重要的影响。由于家有病童而需承担的照护担子，以及各种因孩子疾病所引发的压力，如排山倒海而来的财务困难和身心灵问题，父母在这种种困难面前显得多么地脆弱而不堪一击。儿童安宁疗护照护小组需要通过以下方式协助这些父母进行决策和艰难的交谈：包括处理患病孩子的疼痛和其他症状，照顾父母和家人的需求，如照护协调、安排喘息时间、陪伴度过丧亲之痛并提供社会与情感支持。



Susan Pee医生目前就职于柔佛新山苏丹依斯迈医院（Hospital Sultan Ismail Johor Bahru）担任儿科肾脏专科医生。她毕业于马来亚大学，获得医学学士学位和外科学士学位，后来获得了英国皇家儿科及儿童健康学院（Royal College of Paediatrician United Kingdom）的会员资格。在获得FRCPCH后，成为MRCPCH检查员。她是第四版《Malaysian Renal Replacement Therapy CPG》及第四版《Paediatric Protocols for Malaysian》的作者之一，负责撰写儿童肾脏科章节。她于2013年参与于柔佛新山苏丹依斯迈医院设立儿童安宁疗护部门。



MAPAC
MALAYSIAN ASSOCIATION OF PEDIATRIC PALLIATIVE CARE



V.T.P.



MAPPAC ACTIVITIES...
Volunteer Training Program
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LEARNING ON VOICING
EMOTIONS OF DEATH

P.P.C. Annual Workshop 2021

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



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 MAPPAC

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CLINICAL SERVICES

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- Workshop / Medical Conferences for Medical Professionals
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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.

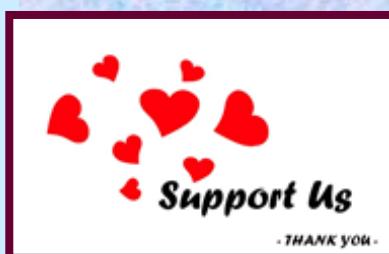
- ◆ **Places of Care**

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.

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