Foreword

Issue no 019
Malaysian Association of Paediatric Palliative Care
Oct 2022

Dear Readers,

We are into our final count down to the 1st NCCPCM on 6th-8th October 2022. There is so much hype and excitement at MAPPAC.The seats have been fully taken up by enthusiastic participants. It will be a dream come true as the event has been postponed on numerous occasions due to the Covid pandemic.

In this issue, we bring you **To Relieve Sometimes** by **Dr Poongkodi Nagappan**. Read on to soak in her experiences and reflections on paediaitric palliative care.

We also have an additional article **Close Encounter with Palliative Care** from **Ms Carmei Wright.** It is her personal encounter with palliative care and how she has taken it further to enrich the minds of the little ones. This is in support of the MAPPAC card making project …. all for a charitable cause.

With these, we wish you many pleasant moments going through the various interests lined up specifically for your reading pleasure . And our warmest wishes to those who celebrate the Deepavali Festival come 24th October 2022.

We welcome your support and in our upcoming activities. Please visit us at :

https://www.mappac.org or
Malaysian Association of Paediatric Palliative Care facebook for updates.

You can also contact us or contribute articles via email to :
michaeltanadrian@gmail.com or shashacure26@gmail.com

MAPPAC Central Committee

MAPPAC Article 1

Issue no 019 Malaysian Association of Paediatric Palliative Care Oct 2022

To Relieve Sometimes

It was pouring outside as I walked into the ward one Thursday evening, feeling tired and hungry from a day in the operating room. "Hi doctor," came a soft voice from the acute cubicle. I turned to find a young mother sitting next to her child. He was only a baby, barely a year old and lying on his side breathing rapidly, despite oxygen supplied by tiny nasal cannula. His wet cough and glassy eyes alarmed me until I remembered that this was the baby with posterior urethral valves and severe renal dysplasia.

In paediatric urology, we rarely encounter death. Our main responsibility is to prevent onset of chronic kidney disease in children with congenital renal anomalies, and to help children cope with their disabilities in order to lead as near normal and independent a life as possible. On rare occasions, we have difficult conversations with parents. This particular baby had undergone valve ablation, and yet his serum creatinine continued to double every few weeks.

The paediatric nephrologists who care for such patients often ask if anything can be done to slow down the deterioration in renal function. So I assess the bladder pressure with a urodynamic study, ask the mum to perform clean intermittent catheterisation of the bladder diligently and think hard on whether a vesicostomy procedure to continuously drain the bladder would help. In this child, it didn't. So we waited for weight gain so that peritoneal dialysis with Tenckhoff catheter could be performed. By that time, we knew that his dysplastic kidneys would not be able to support him for long. Just as his mother knew.

In children with chronic and end-stage kidney disease, the discussion on palliation occurs when we are not able to slow down renal function deterioration, or when the child is not a candidate for renal replacement therapy. This can happen when the patient's renal dysplasia is advanced and would not improve with measures such as bladder augmentation to reduce bladder pressures. More often, this situation arises when the child has other concurrent anomalies, a genetic syndrome or global developmental delay, that prevents them from leading an independent life.

MAPPAC Article 1

Issue no 019 Malaysian Association of Paediatric Palliative Care Oct 2022

To Relieve Sometimes

In my experience, the correct decision for the child is always apparent, but requires immense courage from the parents and support from the health care professional. The parents would feel a lot of guilt and our conversations should aim to lessen that feeling for them, by not forcing the decision but allow events to unfold gradually while providing clear and honest explanation. These ideals have often been quoted by our forefathers in medicine, **"To cure sometimes, relieve often, and to comfort always."**

To cure sometimes, to relieve often, to comfort always.

- EDWARD LIVINGSTON

Dr Poongkodi Nagappan graduated from University Malaya in 1999. She has a special interest in congenital conditions of the genitourinary tract and genitourinary reconstruction. She is a Consultant at the Urologist Department of Urology , Institute of Urology and Nephrology, Kuala Lumpur Hospital

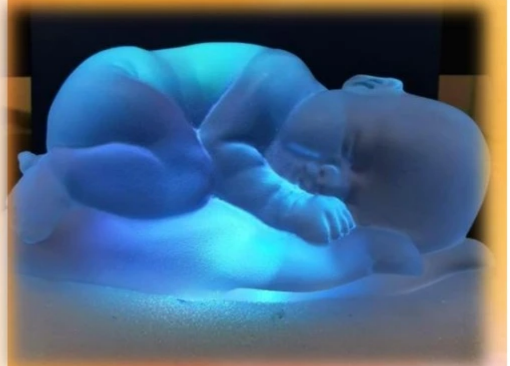
MAPPAC Article 1

Issue no 019 Malaysian Association of Paediatric Palliative Care Oct 2022

有时缓解

To Relieve Sometimes

一个星期四晚上，当我走进病房时，外面正下着倾盆大雨，在手术室里呆了一天，感到又累又饿。“你好，医生。”小隔间里传来一个轻柔的声音。我转身发现一位年轻的母亲坐在她的孩子旁边。他只是个婴儿，不到一岁，尽管有微小的鼻导管供氧，他还是侧躺着呼吸急促。他的湿咳和呆滞的眼睛让我警觉随着想起这是一个有后尿道瓣膜和严重肾发育不良的婴儿。



在小儿泌尿外科，我们很少遇到死亡的案例。我们的主要职责是预防先天性肾异常的儿童患上慢性肾病，并帮助儿童应对他们的残疾，以及尽可能接让他们过着近正常和独立的生活。在极少数情况下，我们会与父母进行“艰辛”的对话。这个特殊的婴儿接受了瓣膜消融术，但他的血清肌酐每隔几周就会增加一倍。

照顾此类患者的儿科肾科医生经常会询问是否有任何措施可以采取来减缓肾功能的恶化。因此，我通过尿动力学研究来评估膀胱的压力，要求孩子的妈妈勤奋地对患者膀胱进行清洁的间歇性导尿，并认真考虑进行膀胱造口术以持续排空膀胱是否真的对孩子会有所帮助。对于这个孩子来说，它没有帮助。所以我们等待这个孩子的体重增加，以便可以使用 Tenckhoff 导管进行腹膜透析。到那时，我们知道他发育不良的肾脏将无法长期支持他。就像他妈妈所知道的那样。

在患有慢性和终末期肾病的儿童中，当我们无法减缓他们的肾功能恶化或这些儿童不适合接受肾脏替代治疗时，我们就会开始讨论关于他们临终治疗的事宜。当患者的肾发育不良处于晚期并且通过膀胱增大以降低膀胱压力等措施都无法改善时，这种情况就能发生。更常见的是，当孩子有其他并发异常、遗传综合征或全身发育迟缓，阻止他们过独立生活时，就会出现这种情况。

MAPPAC Article 1

Issue no 019 Malaysian Association of Paediatric Palliative Care Oct 2022

有时缓解

To Relieve Sometimes

依据我的经验，对孩子的正确决定总是显而易见的，但这需要父母的巨大勇气和医疗保健专业人员的支持。父母会感到很内疚，我们的劝导应该致力于减低他们的这种感觉，不要强迫他们做出决定，而是提供清晰和诚实的解释的同时让真实情况逐渐揭示一切。我们的医学先辈经常引用这些理想关念：“有时治愈，经常缓解，总是安慰。”

Translated by Mr Yew Teck Wah

> **To cure sometimes, to relieve often, to comfort always.**
>
> **- EDWARD LIVINGSTON**

Dr Poongkodi Nagappan graduated from University Malaya in 1999. She has a special interest in congenital conditions of the genitourinary tract and genitourinary reconstruction. She is a Consultant at the Urologist Department of Urology , Institute of Urology and Nephrology, Kuala Lumpur Hospital