



# HKPNA

# Newsletter

Hong Kong Paediatric Nurses Association Ltd. [www.hkpna.com.hk](http://www.hkpna.com.hk)

## Experience Sharing

### Paediatric Palliative Care in Hong Kong

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Palliative care for children is the active, total care of the child's body, mind, and spirit and extends to providing support to the family. It begins when illness is diagnosed and continues as long as the child is receiving care, regardless of whether treatment is directed at the disease, and, for the family, through bereavement if the child dies (World Health Organization definition of palliative care, 2009).

Palliative care represents holistic, child-, and family-centered care, provided by an interdisciplinary team in the hospital, outpatient, or home setting, which aims to enhance quality of life by addressing the physical, psychosocial, and spiritual consequences of illness and treatment.

Hong Kong's prevalence of childhood cancer is approximately 150 per 1,000,000 children. Nearly 45 children die from cancer every year. Similar to Western countries, childhood cancer is the number one cause of death amongst children between the ages of 1 and 14 in Hong Kong and Children's Cancer Foundation (CCF) firstly initiated the Palliative and Home Care Services in November 1999. Every year nearly 70% of the cancer children are under the care of CCF in their advanced stages of cancer.

The goal of CCF is to provide specialized palliative nursing care for children with incurable cancer, in a cooperative effort with fellow CCF professionals and the various disciplines from the attending hospitals that refer the patients, enhancing the quality of their remaining life. After a child's death, bereavement care is provided for the family during this difficult time of emotional upheaval. Palliative care uses a family-centred approach. The child and his/her family are treated as one unit of care. The care and support given to the patient is based on the belief that every day of human life is precious and meaningful, and that every human being deserves dignity and concern from others.

The home care nurse assists the family to take care of the child by teaching and supervising parents in procedures and techniques needed to provide comfort to the child. Through frequent telephone consultations, the nurse is able to update and monitor the patient's condition and give advice to the family as well and when necessary. Thus the child is able to remain at home as long as possible and stay in hospital only when it is absolutely necessary.

There is still no palliative care available for children with other types of life threatening illness in Hong Kong. Since 2011, CCF has aimed at providing palliative care services for those child patients suffering from other life threatening illnesses such as neurodegenerative disease, end stage renal disease, and implemented a pilot program. We hope that we can address those children's needs and learn to provide specialized palliative nursing care services to them and their families through this pilot program.

#### References

A. Goldman (1998). Care of the dying child. Oxford: New York.

S.T. Tang. Taiwan perspectives in palliative nursing care. In B.R. Ferrell & N. Colye (2001). Textbook of Palliative Nursing. Oxford: New York.

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## A Salute to Our Brave Fighters and Their Dedicated Parents

Audrey CHAN, NC (Paediatrics and Adolescent Medicine) Queen Mary Hospital

At one of the HKPNA annual dinners, I remembered our guest speaker Reverend Lee Ching Chee saying that the nursing profession is a “people” profession and is therefore never boring. I agree with her completely. Every patient and family we meet has a story. I would like to share some of these stories that have touched my heart.

### Case 1

About 16 years ago, our PNICU admitted an 11-year-old boy who I shall call TC. He had had flu symptoms for a week and been treated by a GP. His mother decided to take him to A&E but once there he could not get out of the taxi because he could not walk. He was diagnosed with Acute Disseminated Encephalomyelitis (ADEM) after investigations and is paralyzed from the head down. As a result, TC is also ventilator-dependent with a tracheostomy tube.

It was through him that we learned a lot about transitional care of a totally dependent child. It included the psychological preparation of the child and the parents for the transition; the strategies needed to apply for funds for the electrical wheelchair and ventilator; and the communication among multidisciplinary teams of the acute hospital and the rehabilitation centre. In TC's case, the team involvement extended to the rehabilitation unit of The Polytechnic University for their support in choosing and testing the right model of wheelchair. In addition, their expertise was required in designing the tool that would allow TC to operate the electrical wheelchair for transportation. It was a challenge - yet it was overcome. TC used his chin to control the wheelchair and he is still using this method now. It is tiring but the only way he can be mobile.



TC outing in Disneyland this year

In TC's case, transitional care was not only from an acute hospital to a rehabilitation centre. It was also from childhood to adolescence. TC had only been living in Hong Kong for a year when he was admitted to hospital. He was angry with his mother, who had come to Hong Kong earlier, and had given birth to twins. He blamed her for the disease. Furthermore, he felt helpless and depressed on the ward. There was tension between himself and the nurses. Many nurses and volunteers were frustrated because of TC's attitude. We finally understood the reason. It was while we were performing routine turning. We asked TC casually before turning him: “Would you like to be turned?” TC answered angrily: “Do I have a choice or control? If I refuse, will you leave me without turning?” We realised that for all the “good” care we had implemented, we had not taken into account or even considered that TC had grown from a child to an adolescent during the long hospitalisation period. He felt he was not respected.

TC was transferred to the Rehabilitation centre when he was 14 years old. While he continued his schooling, the rehabilitation team worked hard to prepare him for going home. A home is ready for him now. He passed his HKCEE with satisfactory results by his perseverance to have extended examination hours for each subject. A reporter was covering his story. Last year, he finished his Open University of Hong Kong course and is currently taking a theological course.

Although TC is very unfortunate in the eyes of many people and maybe even his own, he does not give up. He keeps in contact with current affairs around him through the computer and conversation. He has a group of friends that are attracted by his courageous attitude towards life.

### Case 2

KM was a Down's baby with congenital complex heart disease and malacic airway. He was the parents' third child. KM's brother and sister were already in secondary school. His father ran a small food stall and his mother was a housewife.

Despite KM's condition, his parents were very keen to take him home. Even though KM had to use BiPAP with oxygen and was on gastrostomy feeding, his parents' decision to care for him themselves was firm. His mother learned all the requisite nursing skills slowly but willingly. KM's brother and sister stayed at home in Tuen Mun so their education would not be interrupted while their parents rented a small flat on HK island. They installed all the necessary equipment for KM there. Although our team was a bit uncertain about their capability, we were moved by their sincerity. We went for a home visit before KM was discharged.

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When that happened, it was with considerable medical advice. His parents took turns looking after him day and night at home. His siblings would come to Hong Kong Island and visit KM whenever they had a holiday.

With his parents' unconditional love and tender care, KM showed an improvement in social interaction especially to his parents. Added to this, he could swallow small amounts of purée. His parents were so satisfied with his progress, they would bring KM back to visit us in the ward whenever he had follow-ups. Sometimes, the nurses would pay a home visit to the family.

Nevertheless, KM died about one year after discharge. His parents and siblings felt no regrets. They had enjoyed the time KM was with them.

### Case 3

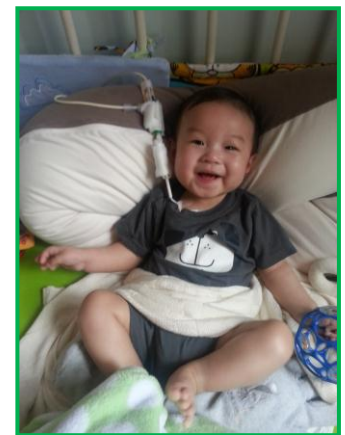
This story belongs to a group of short gut babies, who required long-term parenteral nutrition.

Due to the improved survival of paediatric patients with short gut syndrome and other chronic intestinal failure, there is an increasing trend of children requiring long-term parenteral nutrition (PN).

The most impressive thing about this group of parents is their commitment. When the parents were approached by our team to discuss the home parenteral nutrition plan, all the parents had a unanimous response. Their major concerns were not about the expenses of consumables and the duration of PN but the benefits to the baby's development.

It is quite a burden for parents with a child requiring home PN. It starts from the preparation of the home environment and the stocking up of consumables. The supply of PN is a major issue. Most cases have to return to the pharmacy on alternate days with an icebox to get the PN solution. Usually, it is the father's job. PN administration and monitoring is another issue. Parents have to sacrifice their own time to administer the PN and monitor their child.

When parents are asked about their feelings on looking after a home PN child, their reply is always unanimously positive.



**One of the young fighters –  
a boy with short gut syndrome**

### Conclusion

We are fortunate to be paediatric nurses. We work with young fighters who never give up easily. Children are more daring, courageous and straight-forward. They do not have adults' "complicated" thinking, which sometimes creates more complications in a situation. They give us joy and encouragement in our busy lives.

## **HKPNA Social Event**

### **2013 HKPNA Spring Dinner** CHENG Sau Wai, QEH

On 28th February 2013, HKPNA celebrated the Year of the Snake at the Golden Federal Restaurant. This dinner festivity was attended by over 96 guests and members and friends. In typical Chinese traditional fashion, greetings of good health and wealth were exchanged throughout the night. While some of us concentrated on enjoying the delicious Spring dinner dishes, others concentrated on finding the answers to the fun and tricky questions. Another highlight of the Spring Dinner was the lucky draw. Throughout the night everyone spent in laughter and applause. If you have missed this year's fun and socializing opportunity, and we look forward to see you at the coming year of the Horse spring dinner.



The Happy members of the games-winning table

## Professional Development Activities

Short Course on **Paediatric Nephrology** was held on 16, 23 April and 13 May 2013 with total 164 nurses attended.

**Forum on Child Health: Is Current Education System in Hong Kong Compatible with Optimum Child Growth and Development?** organized by the Hong Kong Paediatric Foundation and Hong Kong Paediatric Society, and supported by HKPNA was held on 16 April 2013 at QEH with 52 nurses attended.

**Professional Forum on Child Health: Critical Appraisal of the Inclusive Education in Hong Kong- what have we achieved and how we can do better?** organized by the Hong Kong Paediatric Foundation and Hong Kong Paediatric Society, and supported by HKPNA was held on 09 May 2013 at QEH with 32 nurses attended.

**13th AGM** on 21 June 2013 was held at Brilliant Harbour Banquet on 21 June 2013 with 143 guests and members attended.

## Forthcoming Events

**Update Series on Child Health 2013** at Jordan Valley St. Joseph's Catholic Primary School on 29 June, 20 & 27 July and 10 August 2013.

**The 45<sup>th</sup> Annual Congress of International Society of Paediatric Oncology (SIOP)**

at Hong Kong Convention and Exhibition Centre on 25 – 28 September 2013.

Please visit:

<http://www.siop-online.org/page/membership>

**The Hong Kong Paediatric Nurses Association and The Hong Kong Paediatric Society jointly organize the annual joint scientific meeting (JASM)** on 8 September 2013 (Sunday) at QEH.

## Overseas Conference

**4<sup>th</sup> International Congress of Paediatric Nursing - Connecting in Children and Young People's Healthcare** in Melbourne, Australia on 24-27 August 2013.

Please visit: <http://www.accypnconf.com.au/index.php>

**3<sup>rd</sup> European Conference on Pediatric and Neonatal Cardiac Intensive Care** in Lucern, Switzerland on 18-21 September 2013.

Please visit: <http://epnicic.com>

## Renewal & Application of Membership

Registered and Enrolled nurses who have experience in paediatric care are welcome as members. Any nursing undergraduate and pupil nurse, of the universities and nursing schools, who has interest in paediatric nursing are also welcome.

Please complete the **Membership Application/Renewal Form** and return it to "Hon. Dep. Secretary, Ms Iris Yeung, DOM (PAED), 9/Floor, Block F, QEH, Gascoigne Road" together with a cheque made payable to "Hong Kong Paediatric Nurses Association Ltd". Application forms can be obtained from HKPNA Hospital Coordinators or downloaded from web site <http://www.hkpna.com.hk>. Kindly fill in your email address when returning the completed form, so that we can keep you informed of the most update activity / course information.

**Life Members** are also welcome to update any personal particulars annually and furnish your email address using the same form.

## Members' Communication Channel

*HKPNA treasures every idea and comment from members. Please forward your suggestions or input in writing to either the President, Ms Susanna Lee at CNO office, Block A, KH or the Hon. Secretary, Ms Ella Ma at WM's Office, Ward EF4, PMH. Besides, you can contact us via email address: [hkpna@ymail.com](mailto:hkpna@ymail.com)*

## Submission to HKPNA Newsletter

The HKPNA Newsletter is published three times annually. Articles such as case studies, research findings, work reports, member's views and ideas are welcome.

Each article is preferably no more than 250 words. Submit either the hard or electronic copy of full text and photographs with subtitles. Author name(s) and contact details should be included. It is the author's responsibility to comply with patient privacy and data protection. Where necessary, informed consent should have been obtained before submission. The Editorial Committee reserves the right to select or reject the submitted article.

Send submission to: Ms Mona Leung, C6 Ward, Tuen Mun Hospital OR e-mail: [leungm@ha.org.hk](mailto:leungm@ha.org.hk)

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