

# Hospice *Link*

SEP 2013 VOL. 23, Nº. 3

*In this issue...*



**Project Happy Apples:**  
NUS-YLL Medical Undergrads  
in Action  
**Page 4**



**Pilot Respite Care Project:**  
Volunteers to the Rescue  
**Page 9**



**My Calling:**  
The Journey So Far  
**Page 14**



**Becoming a Medical Escort:**  
Pillars of Support  
**Page 16**



## Hand in Hand with **star pals**

COLLABORATIVE CARE FOR CHILDREN

By Mrs Jacinta Paglar with Rodney and Luke Paglar

**W**e met the Star PALS team during our son Timothy's last hospital stay.

### **My Son, My Angel**

Timothy was admitted to National University Hospital on 6 May 2012 for aspirational pneumonia, when he had difficulty breathing at home that evening.

My son was a special boy... my angel. He had been born with cerebral palsy and epilepsy. He was also blind, couldn't talk, and had several holes in his heart.

Timothy was not meant to be with us for very long. From the time he was born and with every visit to his doctor at the hospital, we were reminded that his lifespan was short. At a young 16 years, Timothy had beaten a lot of the odds, and lived a comfortable and happy life with his dad, elder brother Luke and me. I attended most to his care.

The day he was last admitted to hospital, it was not expected that he would pull through the

first 24 hours. But being the fighter that he was, he did, and in fact he continued the fight for his life for another two weeks in the Paediatrics ICU. It was then that I was told that should Timothy survive, I could take him home and he would need to be put on an oxygen concentrator, a BiPAP machine (to assist with his breathing). It meant that I would constantly have to keep his airways clear through suctioning. I was familiar with the BiPAP machine, but everything else was new to me, and I was very afraid.

In the end, Timothy stayed two months in the hospital. After such a long hospital stay, we were ready to go home, to a place where perhaps he could be more comfortable, be surrounded by his own familiar things and at least have more time with us again as a family. I felt encouraged when a social worker and some of the doctors from NUH spoke with me about HCA Hospice Care's (HCA) services and palliative care for children with terminal illnesses. When

*Continued on page 8...*

## Hand-in-Hand with Star PALS

... continued from page 1



*The Paglar Family*

## About Star PALS

**S**tar PALS, an initiative by HCA Hospice Care, is a paediatrics palliative care service that provides holistic home care for young patients aged 19 years and below, and extends support to their families.

Patients may suffer from congenital and neurological diseases, to childhood cancers. Multidisciplinary care is provided by doctors, nurses, medical social workers, counsellors and allied health specialists like art therapists.

Besides the core group of medical professionals, Star PALS also actively engages the help of trained respite caregivers, known as Medi-Minders.

they asked me whether I would be interested to use Star PALS' services, I said "Yes" immediately, and the first meeting took place a couple of weeks before we left for home.

### Help and Relief

A day after leaving hospital and caring for my son at home, on my own, Dr Chong Poh Heng, Nurse Lily Li and Nurse Alice Heng paid me a visit. I readily admit that I breathed a sigh of relief the moment I heard that they would be visiting because I was on unfamiliar ground, having to look after a seriously ill child who was not expected to live much longer.

The doctors and the nurses from HCA would visit us weekly, and every time they came, I felt well-supported, encouraged and motivated to do the best for my son. Our goal was to keep him comfortable and pain-free as much as we could.

My fears were slowly eroded as besides getting help with Timothy's medical treatment, I also received a good strong dose of encouragement and empathy, with real sincerity from the Star PALS team. I was always told that the road we faced, though difficult, would never be a lonely one and that there would always be someone there to help us along.

HCA really came through on all its promises: Timothy's medical needs were seen to promptly and professionally at all times. It was like having an extended family who sailed with us through both choppy seas and calm waters. There was always a listening ear and caring presence when Ms Karen Ho, a Star PALS counsellor, was introduced to our family and stayed the course with us. My fears surrounding my son's medical issues were handled most gently by Nurses Lily and Alice, who were always my bastions of comfort, and from whom I drew strength. Dr Chong, especially, gave us personal yet professional medical advice. All this helped me cope with the feelings of sadness and the heartbreaking knowledge that my son was leaving us.

Timothy passed away on 27 November 2012.

At no point did I feel we were left alone to handle this painful journey. We spent four months with our new family from HCA, and we will never forget the kindness, the care and compassion and boundless help extended to my family and me – and especially to our special little angel, Timothy. Were he here in person, I know he would be the first to shout a great big "Thanks!" from the bottom of his heart.

May God bless you all and thank you, thank you, thank you... ♥

