



COLLABORATIVE CARE FOR CHILDREN

By Heather Jones



The British Association has recently started to support Star PALS as one of its nominated charities. This is the only dedicated community paediatric palliative care service serving children living with life limiting conditions and their families in Singapore. Star PALS is a part of HCA Hospice Care, which is a registered charity in Singapore.

Star PALS (Paediatric Advanced Life Support) is an incredible organisation dedicated to improving the quality of life for children who may have neurological or congenital conditions or childhood cancers. A multidisciplinary team comprising doctors, nurses, medical social workers and counsellors works to prevent, reduce and soothe a child's symptoms through regular home visits and a 24-hour on-call helpline as well as providing emotional and psychosocial support and counselling for the entire family. The charity also loans medical equipment to families, arranges days out and makes sure that each child has a cake on their birthday.

The Star PALS Vision

The vision is to be the centre of excellence for paediatric palliative care in Singapore. The aim is to achieve this

with a novel care model; one that builds on the existing services for palliative care while incorporating elements to meet the unique needs of children with life-limiting or life-threatening diseases.

A Volunteer's Story

Kay Thompson is a BA Member currently working with Star PALS. She is also a qualified nurse who came to Singapore in September 2012 and began volunteering for HCA, Star PALS' parent organisation. After meeting Dr Chong, Star PALS' Programme Director, she started to shadow and learn from the Star PALS medical social workers, becoming coordinator for the charity's Medi Minder Volunteers in February 2013.

A Medi Minder is a volunteer who is trained to offer caregivers a few hours of respite, to care for other children in the family, run errands or simply take a breather. Families are offered eight hours of help a month usually in two blocks of four hours. Training comprises of a first aid course as well as basic care for children with life limiting conditions. This training means that Medi Minders do not need to have a medical background but just a heart to care for people and the time to commit to doing so. To provide

continuity of care for a child and to get to know a family, a Medi Minder is required to commit to volunteering for a year, which also means that people keep up their skills. Star PALS tries to match each Medi Minder with a family that requires care.

Kay tells us how Medi Minders can really help families; for example, one particular patient requires their mother to attend school with them. In order to provide a respite day each fortnight, the Medi Minder takes over the role of the carer, in this case the mother, attending school with the young person allowing their mother to shop, clean and cook.

In other instances, Star PALS has been able to offer a spa day to some of the young people's caregivers. This gives them a chance to meet two or three other people in the same position, encouraging companionship and sharing the burdens of a special needs child. Whilst the carers are pampered, the Medi Minders are looking after their child.

For those of us with older children perhaps we have forgotten what it was like when they were small and every trip out involved taking a huge bag of drinks,



snacks and nappies! But for us this is just a stage that lasts for a few years. For parents or carers of a child with a life-limiting condition, lots of equipment is still needed for those ordinary days out. Recently Kay and a Medi Minder accompanied a young man, whose mother is disabled, to the Gardens by the Bay; he would not have been able to make this visit without the help of Star PALS. Medi Minders have also recently helped other young people to fulfil wishes to visit the aquarium and the Night Safari.

Kay enjoys meeting the families that Star PALS cares for and being involved, as part of a team, in planning and providing the best support possible to the young people and their families; she says it is a privilege to be invited into a family home and to take care of their child. She offers the following advice if you are interested in becoming a Medi Minder: most importantly, do not be scared, each Medi Minder is mentored by Kay on their first assignment and the Star PALS nurses also attend the initial visit to a family so the Medi Minder and family can be introduced. She also recommends forming relationships with other Medi Minders so you can learn and share from each other.

The Director's View

Dr Chong Poh Heng is Programme Director of Star PALS and is responsible for overseeing the medical issues of the children and ensuring that caregivers are confident. The team takes great pleasure in celebrating every moment with them and bringing cheer and hope to everyone at home.

All children, including those who are vulnerable, multiply disabled or critically ill, enjoy having friends, going to school and having fun! The multi-disciplinary team in Star PALS sets itself the goal of ensuring that every child under their care should live as well as they can, no matter how much time there is left. It becomes even better when volunteers from everywhere contribute to brighten the lives of these children as much as possible.

How can you help?

In addition to volunteering as a Medi Minder there are plenty of other opportunities to help: For example visiting families, either with or separately from the Medi Minder, to offer different therapies such as a manicure, massage, music, art or craft activity or offering a to share your knowledge with caregivers perhaps by offering a class in relaxation or life

skills such as financial management. Star PALS runs events for families such as family photos and camps, where there are opportunities for people to help with event management, catering or entertaining siblings. You may be able to help fulfill a child's wish by helping with a day out.

Finally, there is of course, always a need to raise funds. A bespoke wheelchair costs \$3,000 – \$4,000 and Star PALS needs to provide ten each year; donations of nearly new toys, books and stationery are always very gratefully received.

If you would like to find out more about getting involved with this amazing organisation, please don't hesitate to make contact today.

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