



## Service Priorities and Programmes Electronic Presentations

**Convention ID:** 505

**Submitting author:** Dr P Y LEE

**Post title:** Associate Consultant, United Christian Hospital, KEC

### **Collaboration with a non-governmental organization in the home palliative care in children with incurable chronic diseases**

*LPY Lee(1), MM Leung(1), Lin Molin(2), YM Ng(1), PK Ma(1), Chiu WK(1), HB Chan(1)*

*1 Department of Paediatrics and Adolescent Medicine, United Christian Hospital 2 Children's Cancer Foundation*

#### **Keywords:**

home palliative care

paediatrics

non-governmental organization

#### **Introduction**

With the continuing improvement in medical technology, children with disabling and incurable chronic illness have their life expectancy much prolonged. It has been the only choice for the families to admit the sick children when their medical dependence increases and the families' physical and psychological needs rise. However, home palliative care has been an overlooked gap for non-oncological paediatric patients. Multi-disciplinary engagement between the family, the hospital and the specially trained paediatric palliative nurse from non-government organization (NGO) has made this home-care approach successful in paediatric patients to live and to leave in dignity. In collaboration with the Children Cancer's Foundation (CCF), our department started the home palliative care programme in 2012 for non-oncological paediatric patients who are medically stable but dependent on medical equipments and continuous nursing care.

#### **Objectives**

1. improving quality of life of the chronically ill child and the family during the child's limited lifespan. 2. enhancing continuity of care of the sick children from hospital to home. 3. recruiting resources from non-governmental organization to help in the community care of the chronically ill children.

#### **Methodology**

We compare the differences on the care of two children with spinal muscular atrophy (SMA) type 1, which is a congenital progressive neuromuscular disease, before and after introduction of the home palliative care programme. Comparison is made in terms of the: 1. quality of life 2. length of hospital stay 3. extent of family involvement in child care 4. medical, nursing and allied health care dependence 5. families' and staff's satisfaction towards the programme Under this programme, the specially trained and experienced paediatric palliative nurses act as a bridge between the patient's family and hospital. The scope of services provided by the home palliative care nurses are summarized.

## **Result**

The medical team and the family unanimously welcome and support the home palliative care programme, because it: 1. boosts up family's confidence in caring the chronically ill children at home. 2. allows the parents actively fulfill their role of nurturing the sick children at home instead of passively visiting the children in the hospital. 3. provides tremendous psychological support to the family during the child's deterioration, dying process and even after death. 4. helps the chronically ill children to live with their diseases at home experiencing more quality-time with their family. 5. significantly reduces the length of hospital stay and number of re-admission, and therefore alleviating medical resources and workload of hospital staff. Our department is piloting this programme with the Children's Cancer Foundation. The positive feedback from hospital staff and family confirms the feasibility of the collaboration between a HA paediatric department and an NGO specialized in home palliative care. In the future, more suitable children and families will be recruited into this programme. We are looking forward to organizing educational case-sharing forums to arouse awareness among medical staff and the public.