

# *Pediatric Palliative Care Interventions*

## **Current scenario:**

Approximately, 250000 of new cases of childhood cancer, worldwide India accounts for 20%. Survival rates of children with cancer in India are currently between 20% and 30% while global survival rates are about 80% - 90% in high-income countries.

Palliative care is specialized care for people with serious illness. This type of care is focused on providing relief from the symptoms and stress of a serious illness and can be used at any stage whether that illness is curable, chronic, or life-threatening. It can also be used to reduce or control the side effects of cancer treatments. The goal is to improve quality of life for both the patient and the family.

The importance of palliative care is recognized all over the world. When a child is diagnosed with cancer, treatment should consist of curative as well as **palliative** care. Proper pediatric palliative care improves the child's quality of life and if in case of relapses or the child becoming terminally ill, enabling the child and family to spend their last days together with dignity. Unfortunately, in India, due to late detection and diagnosis of child cancers as well as the high cost of treatment, 70% of children do not survive. **This very low survival rate implies that there is a large group of children in need of palliative care. However, in India there is no established system for this most basic and essential need.**

Across Delhi NCR, other than a 6 bedded Pain and Palliative Care Clinic in AIIMS, Home Care Services at Rajiv Gandhi Cancer Institute and those offered by Can Support, and the Hospice at Shanti Avedna – all catering to both adult and children there is no dedicated service for pediatric palliative care.

CanKids model of Change for Childhood Cancer in India – which currently provides social support services, social support teams, and now also dedicated nurses – to 65 treating cancer centres – required a focused program of training, capacity building, patient support and interventions for pediatric palliative care. Across the country there are few and intermittent activities to provide this support.

Given relatively underdeveloped palliative services in India this required CanKids to set up and maintain a dedicated pediatric palliative centre (PPCC) which it has done, beginning in July 2012, initially on one floor which now is extended to two floors of its Gautam Nagar building in New Delhi (close to the major hospitals of AIIMS and Safdurjung). This is among the country's first, if not the only service of its kind.

CanKids Pediatric Palliative Care Centre in New Delhi is providing a model of holistic Palliative care support for children and their families as an integral component of the CanKids Model for

change for Childhood Cancer in India. The only one of its kind for children's palliative care in India, this Inpatient and Outpatient service is a flagship project to provide direct palliative care service to children being treated for cancer in Delhi hospitals and for training and building capacities in Children's Palliative Care across the country.

The Rationale for a Pediatric Palliative Care Centre is to develop a model of holistic Palliative care support for children and their families as an integral component of the CanKids model of Change for Childhood Cancer in India.

The following are the 5 palliative care interventions:

**INTERVENTION 1 - Strengthening and Running IPD and OPD Services for Palliative Care services in Delhi NCR and as a Hub and Service center for all Palliative care services PAN India**

- Government hospitals are currently overburdened, due to sheer number of patients they are getting on a daily basis. Expanding of the PPCC services would decrease the load in the bigger hospitals; redistribution is crucial and important as Annual Childhood Cancer diagnosed in Delhi increases day by day. Numbers requiring palliative care (approx. 80% of the total). Poor quality of life, uncontrolled pain and symptoms, difficult deaths, prolonged grief of children suffering from Cancer.
- Children discharged from oncology wards when "no further cure is possible". At this stage pain and symptom – physical and/or emotional- management and counseling of parents are done preparing them for various eventualities they may have to face once they go back to their villages in distant states. When they are unable to return to their villages due to the condition of the child and or it is the child's and or family's wish to stay at PPCC and live the remaining days they are welcomed. Symptoms are managed and very good end of life care is given.
- Children with symptoms as a result of the disease or treatment during the curative phase- Pain and symptom management, Relapsed, terminal ill patient, Post BMT, Pre & Post-op care, Wound Management, Ambulatory antibiotic clinic, Physiotherapy Support, Psychological Support: Individual/group support and counseling
- Respite care to the parents, education about managing their children during the curative or palliative phase.
- Newly diagnosed cancer patients with advanced disease from outlying areas who are yet to be seen in the oncology units.
- Children may be admitted at any stage during their cancer journey into child friendly, single or shared wards on two dedicated floors with bed-side accommodation for parents/carers. They receive holistic care to address the physical, emotional, psychosocial and spiritual impact of their illness.

**INTERVENTION 2 - CAPACITY & SKILL BUILDING (CSB):** Capacity building, training and sensitization of Doctors, Nurses and Social Support Team social workers and front line staff and empowering CanKids staff to deliver quality palliative care including end of life care for Children in India.

**INTERVENTION 3 - Patients and Parent Engagement and Education:** Imparting Education & empowering of parents to manage their child symptoms and pain during treatment and in terminal stages.

**INTERVENTION 4** - Pediatric Palliative Care PAN India: Reintegration, community outreach & awareness. Providing Palliative Care Guidance, advice and support to the Social support teams at the 86 Cankids Hospital Support Units (CHSUs) to provide patient support, counseling, transitioning to and from the local treating centres to the palliative centres, if any

**INTERVENTION 5** - **QCRI**: Social Support OPD, Relapse Project, Terminal and Bereavement Support Project, Bone cancer Project.