Celebrating 5 years of CanKids Pediatric Palliative Care Center - New Delhi

August 14, 2017

Introducing Pediatric Palliative Care

Pediatric palliative care is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancing quality of life and includes the management of distressing symptoms and provision of respite and care from diagnosis through treatment and, where necessary, into death and bereavement.
History of CanKids Pediatric Palliative Care Centre (PPCC)

On 14th August, 2012, 5 years ago, Cankids inaugurated the 1st Pediatric Palliative Care Center in India – as a 10 bedded inpatient and outpatient service in Gautam Nagar, bare 2 kms away from All India Institute of Medical Sciences and Safdurjung Hospital.

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.

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 paediatric palliative care. CanKids PPCC
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 model Center also aims to be the flagship from where we seek to scale up pediatric palliative care at other cancer centers where Cankids runs Hospital Support Units (CHSUs) Pan India. We have recently started developing our training center which aims to builds capacities on different aspects of palliative care to the community at large.

Not a Hospice’ (a term with negative connotations in India), this beautiful facility provides palliative care in every sense of the word through the cancer journey of the children who are looked after here from moment of diagnosis – offering pain and symptom management, counselling, spiritual support, terminal care and bereavement support

OUR KEY INTERVENTIONS OF THE PPCC INCLUDES

Patient support services-

- Round the Clock Palliative Care center Doctors & Nurses
- 10 Cubicle ward & OPD on two floors
- Pain and symptom management.
- Wound management and ambulatory care
- Medical and financial support
Physiotherapy services.
Psychological support services
Therapy and wellness center
Terminal care and bereavement support
Parent Education and training for Care givers & professionals

Social support services –
Kitchen cafeteria and nutrition support.
Entertainment and education.
Spiritual support.

MILESTONES

• Inaugurated Aug 14, 2012
• Nursing home registration Nov 23, 2012 & Morphine license Feb 4, 2015
• Mankind Charitable Trust- Dave & Rani Mann - Agreement of support for 5 years Feb 2013 & + Cipla Foundation, Sept 2016
• PPCC headed by: Dr Anjay Babu, Dr D.P Singh, Sister Hanife MacGamwell, Huma Anis.
• Advisory support Dr Lindsay Crack (Oct 2013 onwards), Julie & Peter Richardson, Dr Veronique Dinand
• Ambulatory Care services for AIIMS – March 2016
• Social Support OPD March 18, 2017

Achievements of our Pediatric Palliative Care center

• The PPCP has a complete team of qualified doctors, caring nurses, nursing aides, physical therapist, and psychologists. Having 2 full time doctors, 6 nurses, a psychologist, physiotherapist, patient navigators
and social support staff, with close support and guidance provided by a UK based Palliative Care specialist makes a huge difference in the care that we provide. As our presence in the medical community is strengthening and widening and our team is getting more empowered we are getting closer to our vision of having a flagship pediatric palliative care services.

- We have our own Morphine Licence as a recognized medical institution for palliative care, from the Drug Comptroller General Delhi Government per new requirements stated by the changes to the Narcotics laws.

- We are also a recognized institution by Delhi Municipal Court. We can register deaths on line and print official death certificates.

- Transfers to PPCC from the hospitals are getting closer to becoming more seamless as we now have a better dialogue with the treating doctors and the nursing teams at the hospitals. This is a big step to better the continuum of care.

- In its 5 year history, the PPCC has provided in-patient palliative care to 1141 children and their families – of which 517 were new admissions and 642, were re-admissions.

- At the PPCC the OPD provides ambulatory service for injecting of IV antibiotics for children under treatment at 2 of our CHSUs, viz AIIMS – the pediatric oncology division and the AIIMS Institute Rotary Cancer Hospital, to supplement their services, in a shared care model. In the last year we have catered to 729 patients for Ambulatory Care.

- On 18th March this year we have started a special 1st of its kind in India Social Support OPDs to provide a holistic approach to the pediatric cancer patients from the Center.-- which runs 24x7 with 11 support services and 68 social support clinics each week. During its first three months it has catered to 714 children with 2256 times visits. This OPD offers not only offers ambulatory care but also take care of the symptom, pain and wound management, provides Psychological, Spiritual, Nutritional, Physiotherapy, Educational and Financial support and patient navigation services provided by respective trained professional.

The Cankids Pediatric Palliative care model and Center was presented at the SIOP 2015 in Cape Town and IAPCON 2016 in Pune and at HPMA /HPNA annual conference in Chicago. All were very well received. Good connections were made and new invitations were received.
This Pediatric Palliative Care Center is my dream come true. When Kabir, my son, refused as 2nd Bone Marrow Transplant after his first one had failed, he wanted nothing more than to come back to India – to his home.

We made the journey back home, with our hearts heavy, but with Kabir’s courage giving us all strength to get through the days ahead. His treating Doctor from Georgetown University Hospital Washington DC, Dr Aziza Shad, actually accompanied us.

There was nothing in the way of Palliative care support in Delhi or even in India. We converted his room into a mini hospital, flew in pain patches from USA and did our best to keep him free of pain and give him the comfort and succour he needed.

I think, as much as every child with cancer deserves the best possible treatment, care and support, he and the family need palliative care, pain management, symptom control, counselling and emotional support through the long and tortuous journey.

We have made our Center beautiful – an oasis of calm and joy. To bring moments of strength and succour to families to face whatever lies ahead.

Our children deserve the best. This is the beginning of a new journey, I hope you will stay with us to bring the best of the world’s care to our children in India.

Sonia Sekhri- Executive Board Member
CanKids...KidsCan
Aug 14, 2012
Best Regards

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