

Bai Jerbai Wadia Hospital establishes a Paediatric Palliative Care Unit in India

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The goal of palliative care is to improve the quality of life of patients with serious illnesses. It prevents or treats symptoms and side effects of disease and treatment, along with tackling emotional, social, and practical problems that illness brings up. Hence, Bai Jerbai Wadia Hospital for children, Parel, Mumbai, is the first exclusive pediatric Hospital to start a paediatric palliative care unit in India, on May 1, 2019, to enhance the quality of life of children, and help the caregivers too.

Paediatric palliative care is the need of the hour. Many children with life-threatening conditions like cancer, HIV/ AIDS, drug-resistant tuberculosis, and life-limiting conditions such as chronic organ failure, genetic diseases, and neurological diseases, need palliative care support. India mainly has palliative care services for adults and for children suffering from cancer. Children with complex or chronic conditions represent an under-served population, and their families are often drained emotionally, financially, spiritually and physically. To help these children, the Bai JerbaiWadia Hospital for Children established the Palliative Care Unit in Mumbai and first of its kind in the country in association with Cipla Foundation. This will be the first structured palliative care service for children and will include palliative care support for cancer as well as non-cancer conditions.

The palliative care team at this large multi-specialty hospital is composed of doctors, nurses, counselling psychologists and social workers, in collaboration with physiotherapists. Furthermore, nutritionists will provide additional support to improve quality of life for children, along with their families. This team of experts will work to empower caregivers and provide support to the child and family, alongside the treating team. In a unique approach, the palliative care team will be present in the wards where children are receiving treatment so that palliative care can be easily integrated along with treatment to maximize outcomes for patients and their families.

The unit is established to see in-patients and out-patients, in order to manage pain and other distressing symptoms and to provide psychosocial and spiritual support via holistic approach. Planning home care and training relatives to take care of the child at home is an important aspect of the team work. Good communication is extremely vital while providing support for care-givers and siblings with psychosocial and spiritual distress, particularly when the child is reaching the end of life, and after. Sensitization and awareness among health professionals is a part of the team's activities.

Palliative care should be provided from the point of diagnosis throughout the child's life, embracing physical, emotional, social

and spiritual needs through treatment till the end and beyond as bereavement support for the family. It is appropriate at any stage of illness, and can be provided together with curative treatments. In cases, where cure is no longer possible, improving the quality of life becomes the main focus in caring for the child and family.

Dr Minnie Bodhanwala, CEO, Wadia Hospitals, Parel, said, “ There are 420 million children in India, and roughly, 1 in 1,000 children in India or world, need palliative care. 4.2 lakhs children under the age group of 18 may need palliative care in India. To help children with life limiting or chronic illnesses like severe malformations, organ failure, and genetic diseases, along with caregivers, on May 1st, paediatric palliative care services have been started in the Bai Jerbai Wadia Hospital. Unfortunately in India, palliative care is for oncology patients, and there are no centres dedicated for ailments like organ failure or genetic diseases. Moreover, it is also not recognised by the health professionals, as there are so many chronic diseases with the lack of treatment. Bai Jerbai Wadia Hospital for children, Parel, Mumbai, is the first exclusive paediatric Hospital to establish a paediatric palliative care unit in India. Since May 2019, out of the 400 admissions in the hospitals, 40 patients are being taken care by the palliative care team.”

“The purpose of palliative care is to ease your child’s pain and other symptoms and provide emotional and other support to your entire family. It is a partnership between your child, your family, and the health care team. This team listens to your preferences and helps you think through the care options for your family. They will work with you and your child to make a care plan for your family. The team will help children gain the strength to carry on with daily life. Thus, it meets the emotional and developmental needs of the patients. Not only this, the team may help patients and families explore their beliefs and values so they can move toward acceptance and peace,” she concluded.

Romana Hamid, Managing Trustee, Cipla Foundation said, “Cipla first started a dedicated palliative care centre in Pune over 20 years ago. The need for palliative care in India is growing and we have been striving to make palliative care accessible to as many patients and families, as early on as possible. The partnership to launch the first paediatric palliative care OPD at Bai Jerbai Wadia Hospital is a step in this direction. We are proud to work with Bai Jerabai Wadia hospital in this unique endeavour and also towards a shared vision of ‘Caring for Life’, especially for the most vulnerable groups such as children who are living with life limiting and life threatening conditions.”