

# PAEDIATRIC SUPPORTIVE CARE

for children with chronic, advanced, or incurable diseases





SUPPORTED BY



Chennai  
Willingdon  
Corporate  
Foundation



A CHILD'S RIGHT TO GOOD HEALTH CARE, AUTOMATICALLY INCLUDES PALLIATIVE CARE, WHICH IS AN INTEGRAL PART OF ANY MEDICAL INTERVENTION.

Palliative care means holistic or complete care – physical, emotional, spiritual, financial, social, and psychological support offered to a patient and the family as a unit.

Palliative care is patient-centric care that begins at the time of diagnosis, and 'care' continues even when a 'cure' is impossible. It aims to improve the quality of life by reducing pain and suffering.





## WHAT IS PAEDIATRIC SUPPORTIVE & PALLIATIVE CARE

“The active total care of the child’s body, mind, and spirit, which involves supporting the child’s family/caregivers”.

- The World Health Organization (WHO).



## WHY DO WE NEED PALLIATIVE CARE FOR CHILDREN

The Lancet estimates that 98% of the 2.5 million children requiring palliation worldwide are from low- and middle-income countries like India. These are children suffering from cancer, irreversible organ failures, HIV/AIDS, neuromuscular or neurodegenerative disorders, severe cerebral palsy, etc. The diagnosis and subsequent treatment affect the entire family, which may lack the resources to cope.



The need for Palliative Care for children is huge, and there is so much to do for them and their caregivers. To provide quality care, care providers should be empowered through training and sensitisation. Golden Butterflies Children's Palliative Care Foundation's objective is not only to empower children and their caregivers, but also health care providers.

Children facing life-limiting and life-threatening illnesses have the right to receive good palliative care. It is equally incumbent on society to arrange for the same by trained medical professionals and sensitized general public.

A holistic, professional, and active approach to caring is not restricted to pain and symptom management. It involves providing support to the whole family. Paediatric Palliative Care begins when the illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease.





## GOLDEN BUTTERFLIES PAEDIATRIC SUPPORTIVE CARE

Golden Butterflies Children's Palliative Care Foundation is a not-for-profit, registered public charitable trust located in Chennai, registered in February 2018. It is dedicated to serving the needs of underprivileged children (and their families) suffering from chronic, advanced, or incurable diseases. We provide supportive care from the time of diagnosis with psychosocial support and art & recreational therapy, as well as transportation, medicines, hygiene, nutrition & financial assistance when needed. Palliative care is given to the terminally ill child, and bereavement support is given to the family following the child's death. Golden Butterflies is a secular organization providing equity in access to Paediatric Palliative Care.





## PSYCHOSOCIAL SUPPORT

Counsellors / Social Workers / Psychologists

- Psychosocial interventions (counselling) are provided based on need – in person/ over the phone.
- Palliative and end of life counselling provide a support system to help child-patients and families live as positively as possible until death.
- Grief and Bereavement counselling is provided to address the child patients' and caregivers' practical and emotional needs.
- General nutrition, hygiene, and empowerment counselling are provided to child patients and families.





## ART & RECREATION INTERVENTION

- Child-patients are engaged in Art/ Recreational activities as they are therapeutic, help in muscular relaxation, and improve motor skills and eye coordination.
- Trained Medical Social Workers, Nursing Officers, and WINGS (volunteers) facilitate the sessions; the interaction is important for wellness.
- Interventions bring out creativity and keep child-patients intellectually active.
- Group activities create good bonding, a sense of safety, love, and affection for each other





## NON-FORMAL EDUCATION

- NFE (non-formal education) are 'bridge classes' for child-patients, whose education is interrupted by illness and treatment.
- These sessions improve the child-patient's skills and competencies.
- Child-patients feel confident to re-join school after their treatment.





## IMPORTANCE OF INTERACTION WITH SIBLINGS

- Siblings are included in all activities and counselling sessions. Equal importance and care is provided to the siblings.
- Continuing education for the sibling is very important.
- Involving siblings in the child-patient's daily activities is very healthy.





## EMPOWERING CAREGIVERS

- Creating a 'safe space' for the caregivers and families of child-patients, whose children are in treatment/ remission and who are bereaved.
- This space helps the caregivers to ventilate the challenges they face during their child's treatment and learn from each other.
- It helps them to understand the need of self-care.
- Livelihood support empowers the caregivers to take care of the child-patients' needs more confidently.





## SUPPORTIVE CARE AT HOME & HOSPITAL

(Medical Director, Chief Medical Officer, Nursing Officers, Medical Social Workers, Psychologists, Physiotherapists, Nutritionists, Counsellors, and other Professionals involved in care)

- The multi-disciplinary team (MDT) reaches out to the families on a need basis, at homes and in hospitals.
- Personal visits create a safe space to express their emotions and feelings.
- MDT understands the situation and challenges of the family during the home visits, and encourages the community to support the family.





## END-OF-LIFE / BEREAVEMENT SUPPORT

- Support helps the family to grieve and makes them move forward after the child's death.
- Family is guided to accept the child's passing without guilt.
- Financial assistance and livelihood support help the family be more confident in dealing with situation.





## THE NEED TO CREATE COMPASSIONATE COMMUNITIES

- Awareness about Paediatric Palliative Care among the medical fraternity, nurses, social workers, psychologists, and other allied healthcare professionals builds support for holistic care.
- Sensitization at the community level helps with early diagnosis and referral of patients.
- Awareness of PPC among the General Public dispels myths and creates more understanding & compassion towards children diagnosed with long-term illness.





# COME FLY WITH US

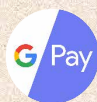
## BE THE BRIDGE

S. No.	GIFT TODAY	Amount (in INR)
1	Patient Support (Nutrition/Sanitary Kits/Transport)	₹ 1000 - 5000
2	Medicines / Scans / Lab Tests	₹ 5000 - 10000
3	Workshops (Counselling, Art & Awareness)	₹ 5000 - 10000
4	Chemotherapy / Radiation	₹ 25000 - 50000
5	Corpus Fund	Any Amount
6	Toy & Art Materials	New/Good Condition

### BANK ACCOUNT DETAILS

Account name : Golden Butterflies  
 Account No : 6678025465  
 Account Type : Current Account  
 Bank Name : Indian Bank  
 Branch : Chetpet, Chennai  
 IFSC code : IDIB000CO17

### SCAN TO PAY



Reg. No.: CSR : 00002360

\*Your donation must be accompanied by the following information (mandatory, as per the recent changes in government rules for NGOs 2020):  
 Full Name / Address / E-mail / Mobile number / PAN number.

**80G IT exemption Reg UR No: AACTG9844Q/05/18-19/T-0829/80G**

Please email the transaction details to: [letschat@goldenbutterflies.in](mailto:letschat@goldenbutterflies.in)

DISCLAIMER: All photographs of pediatric patients in this book are used with the explicit consent of the child and consent of his/her parent/guardian. Names of child-patients have been anonymised to maintain confidentiality.





**GOLDEN BUTTERFLIES**

CHILDREN'S PALLIATIVE CARE FOUNDATION

*- Lil Lives Matter*

📍 6, Ashwin Flats, Prof. Subramanian Street, Kilpauk, Chennai - 600010

✉️ [letschat@goldenbutterflies.in](mailto:letschat@goldenbutterflies.in) 🌐 [www.goldenbutterflies.in](http://www.goldenbutterflies.in) ☎️ +91 87544 48845

📘 [goldenbutterflies](#) Childrensfoundation 📷 [childrensgoldenbutterflies](#)