

**Pain Relief and
Palliative Care Society**
Hyderabad

Pain Relief and Palliative Care Society

Annual Report FY 2022-23

**Submitted by Dr Manjula Bhagavatula
Honorary Secretary**

President's Message

It is a matter of great pride that in a span of 15 years PRPCS has become one of the largest palliative care service providers in the country. And the fact that we are offering all our services like Hospice and Home Care services totally free of charge is nothing short of a miracle. The credit goes to each one of our dedicated staff of Doctors Nurses Social workers and all others who have made this possible by their sincere hard work.

Mission and Vision

Recognition of the need for a separate specialty of Palliative Medicine by the Government as well as the academia has helped it grow leaps and bounds.

Our organization has also grown along with the changes that have been happening in the country. We have an array of programs to cover different aspects of delivery of palliative care services to the needy. We touch many lives and help them in their last part of their journey. Our mission has been **“A Dignified and suffering free life and death when faced with the challenge of a chronic or an incurable disease”**. We have great satisfaction in claiming that we have been able to achieve this for all the hundreds of patients whom we have taken care of.

Our patients are mostly from the lower socioeconomic background who come from the Government Cancer Institute. Because of the confidence in the empathic care provided by our dedicated team, an increasing number of educated and higher socioeconomic patients are also coming. These patients are referred by the medical fraternity, reach out through the media, word of mouth or the internet. The team has never shown any difference in the care for any of these patients and we as an organization have never charged for our services.



Governing Council

President: Mr JN Jagannath

Vice President: Dr. K. Anita Reddy

Secretary: Dr Manjula Bhagavatula

Joint Secretary: Dr Sreekala Nambiar

Treasurer: Ms Vineela Rapelli

Executive Committee members

Dr Sudha Sinha

Dr Gayatri Palat

Dr Sanjeeva Kumari

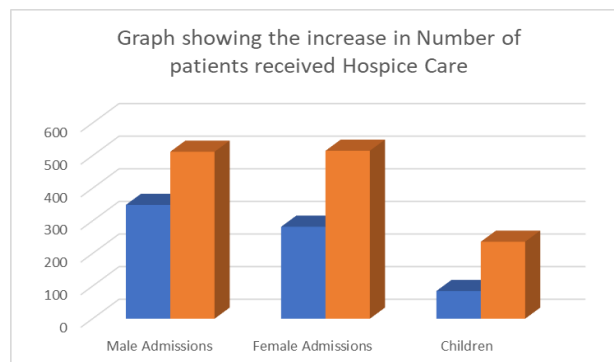
Dr Priya Chandran.



Overview.

Snapshot of patients cared for in our different programs

Kumudini Devi Hospice & Palliative care Centre(Adult)	Male- 508 Female- 525 Total.- 1033
Home care-Life at Your Door Step	Adult visits – 9537 Pediatric visits - 2355 Total - 11892
Mandara Children’s Hospice	In-Patients - 255
Pediatric Palliative Care Program, MNJIO	New Patients- 362 Review Patients- 14941 Total -15303
Pediatric Palliative Care Program, Niloufer Children’s Hospital	Pediatrics - 449 Neonatal – 97 Total - 546
Palliative Care centre, GGH, Kurnool	Male- 144 Female- 145 Total - 289
Palliative Care Centre, Puttaparthi	In-Patients - 231 Home Care visits – 1069



Full time Staff in PRPCS

Doctors	6
Nurses-	35
Social workers/ Counselors	14
Pharmacist	1
Drivers	11
Housekeeping	9
Kitchen staff	4



Kumudini Devi Hospice Team

The Kumudini Devi Hospice has admitted 1033 during the preceding financial year 2022-23. Out of those 1018 were cancer and 15 were non cancer. These patients have been admitted either for the severe symptoms like pain or others, or for the End of their Life. They are given good relief from their symptoms by the efforts of our dedicated staff and many want to go home when they are better. They come back when the disease progresses and their condition deteriorates. We ensure that all communicate the place where they want to be at the end- either hospice or home. The green surrounding and calm and peaceful ambience helps in the care of these patients. All patients are encouraged to come outdoors and enjoy the sun and the greenery which is being lovingly cared for. The Centre completes its 10th year in July 2023. From 2013 we have cared for 7400 patients. We can very proudly say that here we have been able to provide a dignified and peaceful end to whoever wanted to stay here till the end (about 50%). Others were supported at home by visits as well as

being reachable on phone at all hours.



view of hospice premises



Caregivers relaxation area



Caregivers meeting



Mediation session for staff



Recreational activities for patients



Caregivers Psychosocial support by volunteers.

Few Experiences.....

This is a story of a 45 years old doctor Suchi (name changed) working in the Government sector got admitted into our hospice after an unsuccessful prolonged cancer treatment for tongue cancer extending over 4 years. She appeared to be a demanding and authoritative person and due to her appearance asserted herself to avail of all our palliative care services. Initially she would express her anger on our staff and get whatever she wanted. As the days went by her condition deteriorated and became weak. She was being looked after by her husband who works in the software sector. One day, in a reflective mood she narrated her story to our counselor. She had fallen in her youth and married against her parents wishes and moved to Hyderabad from the north. As the years went by the couple developed differences which eventually resulted in separation. She admitted to our counselor that her authoritative and dominating nature was a big reason for the separation. By the time she was diagnosed with Cancer Tongue there



was nobody to look forward to for help. Her ex-husband came to know of her diagnosis and came back into life. Her biggest solace in the days of distress was the fact that her husband was not only back with her but was caring for her in every need. Thanks to the companionship that she found with counselor in the life that she could share her inner most feelings . Being an educated person, she had come to terms with the fact that she would soon die. We ensured that her end was peaceful and pain free. Her estranged husband came back into her life in the last one month she spent in our hospice and was at her side till she breathed her last. Her last words to our counselor was that her husband needed much more counselling to get over the grief than herself.

Mrs. Shivani (name changed), a 23 year old recently married, with a 6 month baby boy was referred to our hospice by the cities leading pulmonologist with a rare progressive lung disease which has no cure. Husband works in the city police force as a constable and was the principal caregiver. Shivani shared her innermost grief and concerns with our counselor, that she knew she was dying, but wanted both her husband and child to be with her and spend last few days with them. But unfortunately that did not happen. Her in laws took away the child with every passing day her husband also began to distance himself from her. These sequences of events caused her more grief and suffering than her imminent death itself. Her desire to experience a little show up for love and affection from her husband remained unfulfilled. Our counselor at least shared her sadness and probably lessened the burden on this young women who eventually passed away.



The **Home Care Program** has been delivering care successfully for the last 15 years with constant addition of vans to cater to the increasing need. Presently there are 10 vans in total (8 vans for adults and 2 vans for children) covering the twin cities. Each van makes about 100 -120 visits in a month and looks after about 950 patients any given point of time (700 adults and 250 children). At any point there are 80-90 patients registered under each van and all the visits are made based on priority, out of which 40 patients(50%) are sick and need support day and night. Our home care team would very calmly guide them through during the night and transport for regular work the next day.



Home care visit



Home care team

I cannot thank Rajitha madam(our nurse)and the palliative care team enough for the incredible care they provided to my bedridden Mother who was suffering from bone cancer. Here are a few points that stood out to me. Rajitha madam was extremely compassionate and empathetic towards my mother and our family. She took the time to listen to our concerns and was always there to provide emotional support. She was highly knowledgeable and skilled in providing palliative care. We were able to effectively manage my Mother's pain and other symptoms, which made a huge difference in her quality of life. Madam was an excellent communicator too and always kept us informed about my mother's care plan. She explained everything clearly and patiently answered all of our questions. The team and Rajitha madam were always accessible and responsive whenever we needed them. They were quick to respond to any concerns or requests we had, which gave us peace of mind.Overall, we are extremely grateful for the outstanding care provided by the palliative care team. They truly made a difference in my mother's life until she lived and helped our family navigate a very difficult time with compassion and expertise. I would highly recommend this team to anyone who needs palliative care."

Wherever possible we have helped the families in rehabilitation and also provide the **Food for survival to families which have financial difficulties**. This program was started during the Covid time when people were unable to go out to work to provide for the family. But the need for this support continues because our home care team visits many of the below poverty line patients who are affected by disease in the family. This puts pressure on the family and they are unable to meet the needs and the little support in form of food for survival kits helps them. Our donors are generously continuing this support



A few testimonials.....

Hi Team of Palliative Care Unit Dr. Sunil Garu and his assistant Mr.Kumar Garu & Mrs.Radhika Garu, We are proud to say excellent service of home visit to treat my mother (Laxmi) name changed from January 2023 to till date without fail coming every 10 days to visit to home and treat to my mom it's unbelievable services to us. Once again thank U and your team sir. 🙏🙏🙏

Hello, my name is Sujan. This is a feedback regarding the home care support staff of MNJ hospital. My grandfather Laxmaiah (name changed)73yrs has been struggling with cancer (carcinoma larynx, stage: 4A) from 1 year and it is a pretty advanced stage. He underwent 33 cycles of radiotherapy and 4 cycles of chemotherapy. After successfully completing the treatment, his body developed some side-effects from the radiotherapy and chemotherapy, then after consulting the doctors, they referred him to pain and palliative care unit. After a few visits to palliative care unit, they understood that my grandfather needs more attention and care, so they sent the support staff Dr. Sunil, councillor Mr. Kumar and nurse Ms. Vijaya to our home. The support staff has been coming to our home on a regular basis and checking up on my grandfather's wellbeing. They speak with us about all and talk in a very soothing manner. The support staff answers our call at any time and whatever the problem maybe, they understand well and give us some or the other kind of solution. The support staff are very kind to us. Whenever they visit our home, we invite them like one of our family members and they are too generous and kind towards us. My grandfather recovered quite well and later scans revealed the cancer had vanished. We felt very happy about that. Even though, my grandfather's disease went away, the support staff continued regularly visiting our home and monitoring his wellbeing. Later on, after 3½ months on the completion of treatment, the new scans revealed the cancer had recurred and he's developing a tumor again in his larynx. The oncology surgeons had planned to perform an operation (total laryngectomy) and cutoff his tumor. The support staff rolled back into action this time more than earlier. I, Sujan, sincerely thank the home care support staff for visiting our home on regular basis without fail and tracking my grandfather's health and wellbeing. I hope people like my grandfather (diseased) should reduce and people like you, should increase. I'm indebted for the amount of care and happiness received from the support staff Dr. Sunil, Mr. Kumar and Ms. Vijaya and the entire network of the team. Thank you.



The feather in the cap is our **Pediatric program** which is one of its kind.

In MNJ more than 15000 children with cancer were seen. Nilofer patient referral is also growing. The effectiveness and impact of the program at Nilofer Children Hospital and MNJ Cancer Hospital has been acknowledgment of the value addition by palliative care departments by including this department as a part of the main stream. The gradually increasing referrals show the difference the team is making in the overall care of the patient and the family. Mandara hospice has helped in giving a peaceful and suffering free end to children and has helped the parents cope with the loss as and when the families choose to come here towards the end. The 10 bedded hospice has a cheerful friendly ambience and the children are engaged in different activities like play therapy, music shows, magic shows ,etc

We also collaborate with Make a wish foundation to fulfill the wishes of these children.



Play therapy for children



Engaging children so that Play is an important part of their life

Visitors and students

Visitors and students come as observers or for training from institutions all over the world like Nepal, Bangladesh, Sri Lanka, Philippines etc. The training is in collaboration with the Palliative Medicine Department of MNJ Cancer Hospital. All Post graduate students, Fellowship students do a rotation at the hospice and in the Home Care which gives them a complete all-round exposure in all models of palliative care delivery.



Visitors and Trainees

1. DNB Palliative Medicine students
2. Radiation oncology postgraduate students
3. Doctors, Nurses and Social Workers from countries like Philippines, Nepal, Bangladesh, Sri Lanka.
4. Medical Students from University of Lund, Sweden
5. Doctors and nurses from national fellowship in palliative medicine/nursing
6. Pediatric palliative care fellows
7. Psychology and social worker students from colleges like Hyderabad Central University and Roda Mystry College of Social Work.
8. Pharm D students from colleges in Hyderabad
9. Volunteers from India and other countries like Canada



Training Programs

PRPCS offers a No of training courses other than the regular teaching with goes on for staff and visitors.

This **feedback is by a caregiver** who sent a message to our President regarding the regular bedside clinical training being conducted by our very senior Nurse Incharge *“Good afternoon!! Hope you're having a relaxing holiday. I am sitting outside in the corridor working and can't help but listen to Mr. Swaroop's very interesting class about wound management, patient care, etc. to a group of interns. I want to say what an amazing instructor he is, and I almost want to pull my chair close and be another student of his:)”*

1. One Year Clinical Fellowship in Pediatric Palliative Care
2. Hybrid Fellowship in Pediatric Palliative Care
3. One month certificate course in pain and palliative for doctors, nurses, social workers and physiotherapists
4. Certificate course in essentials of palliative care
5. Clinical placements for National Fellowship in palliate medicine
6. Training in Pediatric Palliative Care through ECHO model for Sri lanka, Nepal, Bangladesh, and through IAPC Academy
7. Various other sensitization and orientation programs in pain and palliative care

District Palliative program

Since 2017, **PRPCS** has helped Dept of Health and Family Welfare, to establish palliative care centers in all the 33 districts of the state. The centers are doing well.

PRPCS is an **official knowledge partner of Dept of Health and Family Welfare, Govt of Telangana** to establish District based palliative care program in the districts of Telangana since 2017. We continue to support the program by regular mentoring and training of the staff.

The district centers are very useful to the patients because after being seen in the Cancer Institute they are referred to their respective district centers where they are followed up, provided morphine in the district centers and also provided home care. This saves them the effort of coming to Hyderabad to collect medicines.

International Conference of Palliative Care, IAPC was held at Bangalore, 10th to 12th Feb 2023 and palliative care team members and faculty presented various posters and topics during the 3-day program.

1. Hosted the Pre-conference workshop, Bangalore, 9 Feb, on Serious Illness conversation guide with the help of national and international faculty and more than health care professionals including pediatricians, nurses and counselors from India and abroad
2. Sharing experience of Acute Palliative Care Unit at a Government Tertiary Cancer Centre
3. Parents Perspective of Home-Based Paediatric Palliative Care Services – an Observational Study
4. Challenges faced in providing palliative care to patients with end stage kidney disease
5. Addressing the physco- social needs of children with cancer and their families through support group meetings
6. Profile of Children Admitted in a Paediatric Hospice in Hyderabad
7. Legacy and memory making in palliative care
8. Profile of Children in a Paediatric Home Care- A retrospective observation.



Satya Sai Palliative Care Center at Puttaparthi

The new **Satya Sai Palliative Care Center at Puttaparthi** has been growing steadily by increasing the coverage in the nearby villages and planning to increase in-patients from 5 to 10 beds by constructing the first floor. Local volunteers and the Satya Sai devotees are totally committed in taking care of all the non-clinical work of this hospice. The required administrative and coordination work is done by volunteers. They also spend time with the patients and also occasionally accompany the home care team when they are doing a home visit. They have seen 1069 patients in the home care and have treated 231 patients as inpatients.

The strong volunteers group helps in all the non clinical and administrative work. The new challenge the staff here faced was dealing with the death of foreign nationals and coordinating with the respective embassy they were able to every thing required as per law. It was a learning for them.





Financial Summary

All the activities of running an adult hospice, a pediatric hospice, ten home care vans and the programs at MNJ Cancer hospital and Nilofer hospital are entirely free of cost to the beneficiaries. This has been possible because of the continued support of our major corporate, individual donors.

Statement of Expenditure FY 2022-23

FY 2022-23		
Total receipts	Amount in Rs	
Total Domestic Donations	2,71,37,342	
Through FCRA	65,99,101	
Total Donations	3,37,36,443	
Interest	19,45,104	
Total receipts	3,56,81,547	
Total Expenditure	3,03,17,930	
Surplus	53,63,617	
Program	Total Receipts	Total Payments
Hospice	1,18,62,905	87,96,419
Home care	69,30,150	69,30,150
Pediatric Palliative care	1,00,66,000	99,68,179
Kurnool	23,18,986	20,37,120
Puttaparthi	25,58,402	25,86,062
Total Amount	3,37,36,443	3,03,17,930