

## **Annual Report FY2015-16**

### **Activities of Pain Relief and Palliative Care Society**

Dr. Gayatri Palat,

Honorary Secretary, Pain Relief and Palliative Care Society

At the outset, on behalf of Pain Relief and Palliative Care Society, kindly accept our heartfelt gratitude for extending support your invaluable support to our activities. As we enter the new financial year we would like to apprise you of our activities in the year FY2015-16 and also share with you the financial details. Kindly appreciate that any attempt to objectively quantify the work we do, namely providing palliative and end of life care to terminally ill patients is a difficult process as there is no measure what so ever as to how well a patient dies.



***Palliative Care Team***

## **Supporting Department of Pain & Palliative Care, MNJ Cancer Hospital**

This is where the story or rather the journey of the patients who are discharged from their respective wards and are advised that there is no further treatment for them begins. More than 60 patients visit Room No 34 in MNJ Cancer hospital every single day for palliative and end of life care. Patients are segregated into 3 categories; out patients, home care and those requiring admission to the hospice, depending on their condition and the care required. On an average we enroll 2 patients into the Home care program and 2 patients for Hospice admission daily from amongst an average of 60 patients who visit the dept. It is indeed a daunting task to break the bad news and then convince the patient and the caregiver the need to get proper palliative care in the days to come. Total numbers of new patients seen are 2757 and review patients are 7362 at Department of Pain & Palliative Medicine, MNJIO&RCC.

## **Pediatric Palliative Care for Children and Young Adults (0-18 year's age)**

The pediatric palliative care program takes care of children with life-limiting illnesses like cancer, juvenile diabetes, cerebral palsy, muscular dystrophies and chronic renal failure. There is a dedicated team of a full time nurse and a counselor and a doctor, supported by the main team, to take care of children in MNJIO. Trying to ensure continuum of care, the same team goes to homes in the community and the hospice and offers 24 hours phone consultancy. The team has developed a comprehensive documentation system for proper assessment and care of a child's physical

and psychosocial and spiritual needs and to ensure a proper transition of care between different levels of care. Implementing the system of self-reporting of pain by all children admitted in pediatric ward has helped us in early detection and treatment of pain. This is helping us in realizing our goal towards achieving a “pain free ward for children” in MNJIO. Total number of new patients seen is 314 and review patients are 2492 in Pediatric Palliative Care, MNJIO&RCC.

The expenditure incurred in the home care program is mainly for the salaries of the staff, medicines, fuel, phone and other miscellaneous expenses.

Total Expenditure : Rs. 65000/month

Staff Salaries : Rs. 60000/month

Phone : Rs. 1000/month

Others : Play Therapy, activities, toys, medicine, travel and treatment support: Rs.4000/month



**Pediatric Home visit**



**Pediatric out-patient palliative care service**

## **Life At Your Door Step: A Home-based Palliative Care Service**

Home care program for taking care of patients living with life limiting illnesses like cancer, stroke, dementia, paralysis, muscular dystrophies in the city of Hyderabad and Secunderabad is one of its kinds. Three vans each staffed with a doctor, a nurse, a social worker and supported by a physiotherapist covers a distance of approximately 40 km and visits 3-4 patient homes every day. Each van takes care of an average 50 patients. Thus on any given day, about 150 patients are enrolled in our home care programme. Patient visits are prioritized depending upon the condition of the patient. The average total no of home visits per month is 250.

Total no of patients given treatment under this programmed during the year 2015 was as under

<b>Month</b>	<b>New</b>	<b>Review</b>	<b>Total Visits</b>
April 2015	33	151	184
May	33	148	181
June	30	179	209
July	47	217	264
August	51	166	217
September	29	160	189
October	39	143	182
November	28	140	168
December	33	147	180
January 2016	23	176	199

February	35	195	230
March	33	217	250
<b>Total</b>	<b>414</b>	<b>2039</b>	<b>2453</b>

### **Feedback**

*“It was after we interacted with you and your team, we can assure you that ended our sleepless nights. We are extremely thankful to Nurse S who had made few visits to our home and explained the process and to ensure that she does not suffer the pain. We were counseled by Nurse S and team which gave us the immense courage to face whatever was inevitable. We once again end this letter by thanking each and every one from your team which helped us in the dark times of crisis.”*

-- By son of a patient who suffered with stage IV lung cancer,  
Nacharam on Nov 30 2015



**Home visit by Nurse**



**Visit to the patient in temple who doesn't have home**

The expenditure incurred in the home care program mainly are for the salaries of the staff, medicines, fuel, phone, vehicle maintenance and miscellaneous expenses.

Total Expenditure: Rs 2, 10,000/ per month

Staff Salary	: Rs 1, 62,000/ per month
Medicine	: Rs 10,000/ per month
Fuel	: Rs 30,000/month
Phone/ Vehicle Maintenance	: Rs. 6000/month
Stationery/ Water/ Misc etc	: Rs. 2000/month

## **Kumudini Devi Hospice and Palliative Care Center**

### **“Living Well and Dying Better”**

The Hospice at Kukatpally is a 24 bedded facility and has staff strength of 26 consisting of doctors, nurses, nursing In-charge, attendants, cooks, social worker, driver, and administrator and supported by volunteers. In addition to free medical care, we provide free medicines and food to patients and their primary caregivers. We also provide ambulance for transportation of the bodies from hospice to their respective homes.

Total number of Admission: 712, Percentage of children: 9 %

Deaths: 252

Average length of stay: 3 days to 3months

40%- < 7 days

40%- 7-14 days

10%- 14-30 days

10%- >30days

The average occupancy during the year varied between 15 to 18 beds. More than 91 % of patients admitted were suffering from cancer and 9% of patients were suffering from other life limiting illnesses like dementia, chronic renal failure, advanced diabetes, stroke, tuberculosis, HIV and AIDS. Our ambulance, which provides services for transporting dead bodies to their respective homes, transported about 180 bodies in a year.

We believe we have been successful in our endeavor to provide quality care to our patients. While it is difficult to measure the efficacy of service in the field of providing end of life care, the only reliable yardstick is the feedback we get from the patients and their caregivers in our periodic caregiver meetings. We are glad to report that consistent feedback which we got from the caregivers was that their loved ones were mostly comfortable, peaceful and pain free and that they were thankful that their loved ones were finally going to die in dignity and free from pain and suffering. The fact that as many as 132 patients choose to come back to the hospice after getting discharged initially, as their condition becoming stable, speaks for itself.



***Hospice care***



***Child at the Hospice with a Play Therapist***



*Counselor with caregivers*

**Total number of patients seen in the Hospice**

<b>Month</b>	<b>Male Admissions</b>	<b>Female Admissions</b>	<b>Children</b>	<b>Total</b>	<b>Deaths</b>
April 2015	19	20	7	46	17
May	26	21	4	51	12
June	36	22	3	61	23
July	32	25	8	65	25
August	28	24	14	66	21
September	33	31	8	72	29
October	25	36	09	70	20
November	35	27	10	72	24
December	16	22	4	44	17
January 2016	28	20	9	57	11
February	50	30	8	88	21
March	30	29	3	62	37
<b>Total</b>	<b>358</b>	<b>307</b>	<b>87</b>	<b>754</b>	<b>257</b>



The expenditure incurred in the hospice were for the salaries of the staff, food, medicines and utilities like electricity, water, waste disposal, petrol, laundry, patient support, infrastructure and other miscellaneous expenses.

Total Expenditure: Rs 400,000/ per month

Staff Salary : Rs 2, 75,000/ month

Medicine : Rs 30000/ month

Food : Rs 25000/ month

*(We received substantial quantities of rice, dal, oil, sugar and milk in kind)*

Utilities : Rs 70000/ month

*(Petrol, electricity, water, laundry, waste disposal etc)*

## **Rural Community Outreach Program, Chevella Mandal, RR District**

Patients with advanced diseases require continuous care for the rest of their lives and they are in desperate need of accessible medical care to help them cope with their illness. In our rural outreach program in Chevella Mandal in Ranga Reddy District, Telangana State, we provide palliative care to such patients living with life limiting illnesses, in their community.

Two full time village coordinators are employed for the purpose. Doctors, nurses, physiotherapists and social workers make regular visits to the villages, 1-2 times / week and are supported by daily visits by the village coordinators to provide care for the patients in the villages.

As a part of our expansion effort to extend care from current 10 villages to 30 villages, we did house-to-house survey in 30 villages and identified patients with diagnosis like cancer, HIV, Dementia, Cerebral Palsy, Paraplegia, Quadriplegia, muscular dystrophies, Stroke, Juvenile Diabetes etc. Number of patients seen in 2015 from Jan –Dec is as below:

No of patients identified: 199

Diagnosis

Cancer- 23

Chronic renal failure- 04

HIV- 13

Pediatric- 15

Juvenile diabetes- 02

Cancer- 02

HIV- 01

Paralysis – 03

Cerebral Palsy, Intellectual Disability- 05

Thyroid- 01

Others - 01

Neurological

Muscular dystrophy-02

Stroke/ Paralysis- 85

Heart Diseases- 18

Others- 39

Number of meetings held

Women- 25

Youth: 13

Village heads - 20

Awareness Campaign- 05



***A Child with Cerebral Palsy being helped with rehabilitation by our physiotherapist***



***Rural home-based care by a doctor***

The expenditure incurred in the Chevella program mainly are for the salaries of the staff, medicines, fuel, phone, patient support and other miscellaneous expenses:

Total Expenditure:	Rs 60,000/ per month
Staff Salary:	Rs 45,000/ per month
Medicine:	Rs 5000/ per month
Fuel:	Rs 4000/month
Food	Rs. 2000/month
Stationery/ Phone/ Vehicle	
Maintenance	Rs. 3000/month
Miscellaneous/ Unforeseen	Rs.1000/month

## **Training and Education**

The Pain Relief and Palliative Care Society is actively involved in various training programs, awareness campaigns, educational and advocacy activities. On a regular basis, we try to highlight the issue and need for palliative care in media.

### **One-Month Certificate Course in Pain & Palliative Medicine & Nursing**

MNJ Institute of Oncology & Regional Cancer Centre, Hyderabad conducts regular one month certificate course in pain & palliative care for doctors, nurses, social workers, volunteers. The training is supported by visits from many national and internationally renowned experts like Dr. Chitra Venkateswaran, Dr. Mallika Tiruvadanan, Dr. Anil Kumar Paleri, Dr. Biju Raghavan, Dr. Suresh Kumar, Dr. Gillian Fyles, Dr. Stuart Brown, Dr. Francois Bachand, Dr. Eva Brun, Dr. Hidayatullah and Dr. Suresh Reddy. PRPCS supports the training by providing the opportunity to experience the services offered in different settings like hospice, home care and in the rural community". Different faculty and staff from PRPCS also actively engage in various teaching activities.

Profile of the participants who got trained in the year 2015:

Doctors: 20

Nurses: 15

Social workers: 8

Volunteers: 4



***Successful completion of one month palliative care course***

### **Awareness Program**

World Palliative Care Day, October 10<sup>th</sup> 2015 with theme: Hidden Lives, Hidden Patients, at Sathaparni, Hyderabad, with all the donors, well-wishers and volunteers. There was a testimonial from the care givers who received palliative and end of life care for those patients who lost their loved ones.