

# **Report**

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

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### **Supporting the Department of Pain & Palliative Care in MNJ Institute of Oncology, Hyderabad**

On an average 60 patients per day are referred to the Department of Pain & Palliative Medicine, MNJIO for palliative and end of life care. The staff of the society interacts with patients and their caregivers at a personal level to understand their difficulties, emotional and financial problems and help them to cope with the traumatic period they are undergoing. At this stage, the patients are segregated depending on their condition into three groups, of those requiring home care, and those requiring hospice care. They are accordingly enrolled in the respective programs of the society.

#### **Total Number of Adult patients seen in Department of Pain & Palliative Medicine, MNJIO&RCC 2016**

<b>Month</b>	<b>New Patients</b>	<b>Review Patients</b>	<b>Total</b>
April	280	823	1103
May	294	900	1194
June	302	834	1136
July	308	869	1177
August	361	848	1209
September	314	787	1101
<b>Total</b>	<b>1859</b>	<b>5061</b>	<b>6920</b>

## **Palliative Care for Children**

'Pooja asked for a purple cycle. Is there any way we can get her one?'

This was the question on the minds of the doctor, nurse, and counselor of the children's palliative care department at MNJ hospital in Hyderabad last month. Pooja was a 12 year old child with leukemia on chemotherapy since a couple of months. We first met Pooja during a play hour session for all the children in the cancer ward. She danced to a popular Telugu film song and she looked just like any other healthy child, only more brave and lively. She showed us the true measure of her bravery when she started losing her liveliness.

A couple of weeks after that dance we got a referral from pediatric oncology to see Pooja for generalized body pain. She was in severe pain, confined to her bed, and her face had swollen up so we barely recognized her. She talked in a soft voice, telling us about her plans to re-write the school exams she was missing. Her mother started crying because the oncologist had told her that Pooja wasn't doing well. Her blood cell counts were showing a downward trend. Over the next week Pooja got worse. She was passing blood in her urine and vomiting several times a day.

When we saw her one morning, she asked us for a purple cycle.

'But, Pooja, will you be able to ride a cycle now?'

'I will get better soon, and then I will ride the cycle.'

Pooja's cancer was diagnosed to be relapsed and beyond cure and we realized that her purple cycle was something like a last wish. We approached the funds committee of the Pain Relief and Palliative Care Society with our proposal the same day. Pooja was now bed bound and we knew she would most probably never be able to ride that cycle, but that didn't stop any of us. By the next day we had found a second hand pink cycle online and purchased it. We brought the cycle to her bedside and she reached out with her hand and grabbed the handle. Pooja passed away two days later in her sleep with the cycle by her side.

As seen in the table below total number of children admitted in the pediatric ward is an average of 30 per month. All these children are being cared for by

the society's palliative care team consisting of a doctor, a senior nurse, 2 social workers and a play therapist. This is proving to be a substantial value addition to the medical care being provided by the hospital. Our team also identifies and segregates such of those patients whose treatment is completed into those requiring home care and hospice care services of the society.

**Total Number of Children seen in Department of Pain & Palliative Medicine, MNJIO&RCC 2016**

Month	New Patients	Review Patients	Total
April	35	192	227
May	20	231	251
June	34	224	258
July	25	219	244
August	26	231	257
September	34	188	222
<b>Total</b>	<b>174</b>	<b>1285</b>	<b>1459</b>



*Pooja with her favorite cycle*



*Child with counselor*

## **Kumudini Devi Hospice & Palliative Care Centre**

This is a story of one of the patients who was identified and admitted to our hospice for end of life care.

Mrs. Susheela was 50 years old. She was married at a very young age. She has one daughter. The day she was diagnosed with cancer, husband thought she was no more useful for his pleasure and left her and married another lady. Susheela used to work in a hospital as Aaya and bought up her daughter. Her daughter got married. Unfortunately her daughter was attacked by seizures at the time of her delivery, both the baby and her daughter were no more to her and Susheela has become all alone in her life. It took a couple of months for Susheela to come out of these situations. As all this were not enough she was diagnosed with cancer cervix. She used to come to the hospital all alone for treatment. One or two times her sister accompanied her to the hospital and later she was abandoned. Doctors tried their best to cure her disease but due to her aggressive disease Susheela's general condition started deteriorating day by day and she was not fit to undergo further treatment. She was completely transferred to pain & palliative care for end of life care. The same day we treated for her pain and other symptoms and shifted her to the hospice. She was admitted and the staff in the hospice tried to provide the best palliative and supportive therapy. In the initial days she was moving around in the hospice and later she developed Lymphedema in both the lower limbs and has become for her to move or even get up from the bed and few days later she has become totally bed bound. When Susheela was in the hospice her sister came to see her only once and didn't even bother to take care of her. When her sister came and Susheela was conscious we have taken consent from her and sister to cremate her and perform funeral rites. During her final days she used to request the staff for food items of her choice. Call it premonition- Susheela requested to be taken to her former house to say good bye to her friends and neighbors. When she came back Susheela had one thousand rupees with her. She donated the amount to our administrator. Finally Susheela left this world and there was a sense of peace on her. Her body was cremated with proper care and dignity and the funeral rites were performed by our staff.

As seen from the table below each one of the sixty patients who are admitted to the hospice each month has a story to tell like Susheela's. The society and its staff have the satisfaction looking after such patients and ensuring that they have a peaceful pain free and dignified end.

## Admission particulars of Hospice

Month	Male	Female	Children	Total
April	34	26	2	62
May	19	29	8	56
June	21	35	5	61
July	20	22	6	48
August	31	30	3	64
September	24	15	4	43
<b>Total</b>	<b>149</b>	<b>157</b>	<b>28</b>	<b>334</b>

### Life At Your Door Step- A home based palliative care program

This is the story of Mr. Divan Shah. She suffered with advanced Cancer Glottis. He underwent surgery and was left with Tracheostomy. He was referred to palliative care for his pain and tracheostomy care. Wife is the care giver and he has 3 children( girls). They used to live in a small little room which is as small as our wash room. Wife is also a TB patient. He often used to complain of severe pain 10/10 round the neck and difficulty in swallowing and disturbed sleep due to pain and other psychological factors. He was registered for home care as he is the patient from Hyderabad. Home care team used to regularly follow up with the patient trying to address his physical and psychological pain. Divan Shah was a auto driver and he was unable to work to his disease condition. His wife used to go for tailoring work and earn some little money to run the family. Through our organization we used to support the family by providing the basic needs like Rice, Dal, Oil etc for their day to day living. We also admitted in hospice for a couple of days and he was happy when he was at home surrounded by his children. Where as he used to stay in hospice with his wife. The wife was well prepared and explained about his disease condition and his children were too young to understand about their father. One fine day Divan Shah is no more and passed away at home. We also put all his 3 children in a government school. We tried our best to make his end comfortable and peaceful. With the help of donors and well wishers we got his wife a sewing machine so that, she could take care of her children with her lively hood by tailoring by staying at home.

## Home Care Stats

Month	New Visits	Review Visits	Total Visits
April	29	165	194
May	16	182	198
June	31	224	255
July	29	241	270
August	38	227	276
September	46	233	279
<b>Total</b>	<b>189</b>	<b>1272</b>	<b>1472</b>



*Nursing Care in the home care setting*



*psychosocial support at home*

## Community outreach program in Chevella Mandal, RRD Dist

A total number of 261 patients have been identified after a detail survey by our social worker in a cluster of 30 villages in Chevella Mandal about 60 kms from Hyderabad city. All these patients are suffering from ailments like quadriplegia, stroke, juvenile diabetes, HIV, Renal failure and cancer etc. They are in need for quality palliative care which is a far cry in a small village where even the basic facilities are not available. Our staff consisting of a doctor, a nurse, a physiotherapist and a social worker periodically visit the villages accompanied by 2 senior social workers who are based in the

community. 38 visits were made by our team during the nine month period from Jan –Sep 2016. An average of 8 patients who are identified by our local team were provided with medical care and psychological support during each visit. Assistance by way of groceries etc were also provided to those whose means of survival have vanished because of chronic illnesses.

The community outreach program has become very popular in this group of villages to such an extent that society is getting requests from neighboring villages for inclusion in this program.

