

A Mother's Devotion: Nurturing Strength Through Neuropalliative Care

By: Kailash Ganga, PhD Scholar PSW, Neuropalliative and Supportive Care, NIMHANS.

Dr. Priya Treesa Thomas, Additional Professor, NIMHANS

It was another fulfilling day at the Neuropalliative Care (NPC) clinic, where patients and families arrived with hope and trust in our team. As a social worker in the NPC team, I encounter numerous stories of resilience and devotion, but one particular journey has left an indelible mark on me.

Mr. S, a 22-year-old young man, was referred to our clinic for long-term support due to his complex conditions, including intellectual disability, a brain lesion, and being bedridden. His primary caregiver, his mother, welcomed us warmly during our first home visit. She lovingly tried to engage him, asking him to greet us, but he could only respond with a soft noise.

Mr. S's condition was challenging—he struggled with irritability, rashes from prolonged diaper use, recurrent pneumonia, and limited responses to familiar voices. His mother also suffered from chronic migraine headaches and faced financial constraints. Despite these hurdles, her dedication to his care shone brightly.

After assessing the situation during the visit, our team identified several areas where intervention could improve Mr. S's quality of life. We provided an air mattress to prevent bedsores and diapers to ease their financial burden. Speech and occupational therapists were involved to address his needs, and ongoing telephonic and in-person follow-ups were planned.

During subsequent visits, his mother learned safe swallowing techniques, while personal and oral hygiene practices were reinforced. The air mattress brought immediate relief, and her gratitude reminded us of the impact even small interventions can have. Over time, our occupational therapist evaluated his range of motion and posture, advising on assistive devices like knee gaiters and ankle-foot orthoses. His maternal uncle, a secondary caregiver, actively participated, ensuring family support would remain strong.

The family faced procedural hurdles in securing a disability card, but with our guidance, they progressed through the system. Meanwhile, coping mechanisms and caregiving strategies were reinforced through counselling, helping the mother navigate the complexities of caregiving with renewed energy.

A memorable moment came when Mr. S's mother attended a symposium and shared her caregiving journey. Her heartfelt account of balancing her personal life while caring for her son inspired many attendees. She highlighted how the continued support from our team empowered her to provide the best care possible, turning her challenges into a testament of resilience.

This story reminds us of the profound impact a multidisciplinary approach can have in Neuropalliative care. By addressing not only medical but also emotional and practical needs, we help families like Mr. S's find strength and hope. Through collaborative interventions and unwavering support, the mother's dedication was bolstered, and she became a source of inspiration for others facing similar challenges.