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In Alwar, an NGO helps the comatose live with dignity

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NEW DELHI: Shantanu Lodh, a pioneer in performance arts, was in the prime of his career when he met with an accident two years ago which left him in a coma. When doctors couldn't get him out of it, and his friends failed to find someone to take care of him, they shifted him to Anandam rehabilitation centre in Alwar district of Rajasthan that provides 24x7 nursing care to unknown and unattended patients.

TOI visited the centre, 165km from Delhi, and saw a dozen patients, either in a vegetative state or recovering. Lodh, now 56, was one of them.

"His friends came to see him from abroad when he was admitted. His wife still visits frequently," said a social worker with NGO Sapna that runs the centre. Lodh cannot move his arms and legs, and has no memory, but he

did start batting his eyelids recently. It's a sign of a rare recovery from traumatic brain injury.

Dr Deepak Agarwal, professor of neurosurgery at AIIMS, said their research shows 50% of patients with traumatic brain injuries die during treatment and 30% remain vegetative even six months after discharge. "Only a small percentage (15%) became conscious and integrated in society."

Those in a vegetative state or partially recovered need proper rehabilitation which, Agarwal said, is not available in India.

"NGOs like Sapna are doing a great job. But they are very few and have limited resources. On the other hand, the number of

patients requiring rehabilitation is huge and I believe the government needs to pitch in."

Anandam was started in 2007 and has been helping unknown and unattended patients, mostly those referred from the AIIMS trauma centre, live a dignified life.

The patients are discharged from hospital as they do not require surgery or specialised medical equipment, but they need continuous nursing care to prevent bed sores and for feeding.

Social workers and nurses at Anandam look after the comatose patients, clean them regularly and give them timely medication, nutrition and supplements. A doctor visits for medical care, said Anandam in-charge Ranvir Singh.

"Most of the patients brought in a comatose condition do not survive for long, but we feel satisfied even if one of them makes it," said Abhishek Singh, one of the Sapna social workers. Anandam has a wall covered with photos of patients it has reunited with family members. Aatish was one of them. The daily wage labourer from Bihar met with an accident in Delhi, in 2016.

Doctors at AIIMS trauma centre saved his life but he remained in a vegetative state. Sapna members took complete care of him at AIIMS, and shifted him to Anandam when he was discharged. After eight months at the centre, Aatish showed signs of regaining consciousness. One day, he could remember all his details and told the social workers about his family. "He belonged to Nirapur village in Samastipur district of Bihar. His ecstatic family called that very day. It was an emotional moment at both ends. Aatish cried and so did our workers," a Sapna worker said.

A 20-year-old who went into a coma after an accident in Gurgaon was sent to Anandam last year from AIIMS. "His condition was really bad and we thought he would not survive, but within three-four months he regained his memory partially and managed to tell us his address. We informed the police, who contacted the family," Abhishek said. Another patient, Raja, was still wheelchair-bound and barely able to speak when his parents took him home, relieved that he had survived.

Recently, SC decided to allow withdrawal of life support to patients with little hope of recovery. Sapna workers said this should be done in the rarest of rare cases only. “There could be an Aatish or Raja among them. We should strive to save every life possible,” said one of the nurses while changing Lodh’s clothes. The artiste’s shining eyes seemed to express agreement.