

RAJAN'S SAD STORY

A grossly malnourished boy was brought to the Tansen Hospital in the early 2000's. At age seven he weighed only seven kilograms and was severely starved. He was incontinent, and quickly discovered to be severely brain damaged and almost unable to move his limbs. He was said to have had a psychotic mother who had not cared for him. The elderly lady who brought him to the hospital said he had been kept locked up in a goat shed and not fed.

Tansen doctors were astounded by such neglect. The young boy was admitted for care and his health improved, but no improvement was expected to his severely damaged brain. A young Christian woman, recently persecuted and chased out of a hill village as a result of her Christian faith, was employed to be the boy's carer, funded by kind foreigners. For months she slept under his bed until gradually the boy improved and was able to convalesce in an attached building.

After a few months, the young boy, named Rajan, was returned home on the advice of the paediatrician. Sadly, he rapidly relapsed as home care was not a reality, and he was soon readmitted in a similarly starved and abused condition, and the treatment repeated. When admitted for the second time to the hospital, he was barely able to move a finger and could not feed himself or sit up. A balloon to play with encouraged him to move his arms, and with good food and vitamins he started to make some advances. His movement improved, and gradually he began to be able to sit up and feed himself.

In 2005, once Rajan's condition became stable, he was transferred to Nepali Family Inc's first hostel. He joined a group of needy children and the house parents, Seti and Anni, in an old building below the Tansen Hospital. Over time, the number of children in this facility grew, and with this growth, Rajan also grew, and within a few years, he moved to Silom House, a purpose-built facility for this group of orphaned and abandoned children.

Over a period of years, Rajan slowly became able to walk unaided and grew tall, but his severely damaged brain did not recover. All efforts to get him into a local home for disabled children met with refusal, on the basis of his condition not being bad enough and attempts to enrol him in school were also totally rejected. Gradually he became stronger and he could carry food up the very steep hill to the Hospital to take his housefather's lunch, but his speech never developed properly. At Silom, supported by all the children, he was settled and seemed happy.

Over the years, Rajan grew into a tall, strong, young man who was unable to be kept at Silom House with young girls. Without other options, the local administration moved him into a home for psychiatric patients where he was unable to socialise or join in work activities on the small farm. His one friend was another patient from Silom, and they supported one another. The farm was isolated from Tansen, he had little to do and had very few visitors or people who could understand him. Nepali Family Inc continued to pay for him to stay at this facility but had little control over the quality of care.

In early 2019, Rajan began to complain to the staff of abdominal pain but visiting health workers did not think it serious until several months later, when he started to bleed from the bowel, and lost weight. Finally he was investigated and rather lightly diagnosed at the Cancer Hospital as suffering from untreatable bladder cancer. Perhaps an earlier diagnosis might have led to a better prognosis.

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Fortunately Tansen Hospital was in early stages of an Palliative Care Program, and Sister Manju was able to implement a palliative care programme until his death with dignity a few months later in the competent care of Tansen Hospital.

Many of those who had known this tall quiet young man attended his funeral as mourners

This sad story highlights the critical lack of care facilities for patients with severe intellectual and multiple disabilities.