

### By Elisa Patnaik

People with HIV/AIDS in Orissa are ostracised and mistreated by their families, community and the medical fraternity. These conditions have prompted the formation of Orissa's first registered association of people living with AIDS, the Kalinga Positive People's Association.

"I wish I had died immediately after testing positive for HIV/AIDS rather than have to undergo such disgrace, pain and trauma. This is much worse than death," weeps Basanti Jena\* recalling her ordeal at the hands of her family and community members.

When 33-year-old Jena, who lives in a village near Aska in Orissa, tested HIV-positive she was driven out of the house, locked up in the family goatshed, denied adequate food and basic amenities. She was finally rescued by a local NGO working with HIV/AIDS. By then, she was delirious, and infested with ticks and worms.

When plumber Jadu Behera travelled to Surat from his native village in Orissa's Ganjam district in search of better employment opportunities, he contracted HIV/AIDS from a local sex worker and returned to his village fearing ostracism from his fellow workers. Later, following AIDS-related complications (ARC), Behera sought medical help at hospitals in Berhampur. But he was repeatedly turned away. Ill-treatment from his family and exclusion from the community finally pushed him to suicide.

Ostracism, humiliation and mistreatment at the hands of family members, community and the medical fraternity are increasing in Orissa. But there is not a single organisation offering care and support to people living with AIDS (PLWHAs) in the state. The lack of adequate medical care, treatment facilities and socio-economic support from families and the community has driven many patients to despair and suicide.

Cases of PLWHAs being denied treatment at both government and private hospitals are not uncommon in Orissa. Recently, a patient with full-blown AIDS from a village in Bhubaneswar district was brought to a city-based NGO by relatives and abandoned there. When the NGO shifted the patient – who was already showing signs of AIDS-related complications – to the largest government hospital in the capital, they met with stiff resistance from everyone from the wardboy to the doctor. The hospital authorities gave in only after persistent requests and threats from the organisation.

Though the National AIDS Control Organisation (NACO) has laid down specific guidelines for the institutional care and support of PLWHAs, Orissa State AIDS Cell (OSAC) officials claim that "such specifications are mandatory only when a state has been declared to have a high prevalence (of AIDS)". According to officials, since Orissa is a low-prevalence state the emphasis is more on prevention.

According to conservative OSAC estimates, Orissa has nearly 2,000 HIV-positive cases, accounting for a .01% prevalence rate. However, voluntary organisations working in the field of HIV/AIDS feel that the number of patients in the state is increasingly rapidly. Their estimates put the count at more than 8,000. Experts believe that it is irrational and unwise to wait for Orissa to become a high-prevalence state before establishing a reliable care and support programme for

PLWHAs.

Orissa's first registered association of PLWHAs, the Kalinga Positive People's Association, has recently been formed in Ganjam district by Aruna, a voluntary organisation working in the field. "After rescuing a number of HIV/AIDS patients from dire situations we finally decided to initiate a common platform to address their problems," says Aruna's Loknath Mishra.

With more than 100 members, the Association has been fighting for the rights and dignity of PLWHAs in the state. Nearly all its members either suffer periodically from ARC or full-blown AIDS, with diarrhoea, continuous weight loss, cough, loss of appetite, multiple infections, tuberculosis and low-grade fever. Medicine, nutritious food, treatment, regular counselling and the mobilisation of family support are what is required. "Unless we address all these issues and needs specifically, we cannot ensure the active participation of PLWHAs," explains Mishra.

The occupational rehabilitation of both infected and affected persons is another important challenge for the Association. Low/negative awareness, myths and misconceptions, and the fear of ostracism prevent many people in Orissa from even reporting their HIV-positive status. "They are willing to confirm their status only after symptoms appear. But we feel that the Association will be strengthened only after involving more positive people at the HIV stage because of their (comparative) physical fitness and comparatively longer life than persons in the ARC stage," says a concerned Mishra. Four members of the Association died within a month.

Although people join the Association with high expectations, the Kalinga Positive People's Association finds it difficult to meet all their needs with limited means and support. Thirty-two-year-old Malati Beuria who contracted the virus from her husband, joined the Association after her husband's death in the hope of rehabilitation and financial assistance. She and her 10-year-old daughter were driven away from her parents' and in-laws' houses. "The Association helped us in many ways," she says, "but I still do not have a steady source of income and I worry about our future."

A possible remedy, many believe, is mass awareness and sensitisation.

\*Names changed to protect identity

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