

I haven't let TB hold me back - Swami's story



Swami, leading a group discussion at his school's Health Support Group

Swami is 17, an intense and thoughtful young man who is extremely protective of his 9 year old sister Vennela. Swami and Vennela are orphans who have been living with HIV since birth.

Their parents were both HIV positive, although it was TB that claimed their lives. Where they live, about 5% of the population is HIV positive, and TB is the most common killer of people living with HIV (because HIV weakens the immune system, allowing the TB bacteria to take hold). Importantly, TB can kill extremely quickly in someone who is HIV positive so early diagnosis is vital. But poverty, lack of awareness and the stigma of both diseases can mean that people often do not seek treatment soon enough.

Swami and Vennela now live with their uncle, a rickshaw driver. Their Aunt sadly left - like many people her lack of knowledge about diseases like TB and HIV meant that she feared that she would become ill or tainted by the stigma of living in the same house.

"Coming into contact with VMM has been a lifeline. We receive nutritional

support from them, which is a great help because my uncle does not earn a lot. We belong to our local VMM

Child Support Group, where we learnt about keeping ourselves healthy, prevention of transmission to others, caring for others with TB or HIV, and first aid. So when Vennela started to cough and lose weight we knew that she had to go to a doctor quickly. I went with her to her appointments and made sure she took her medicine. And when I was ill and felt nauseous, she helped my uncle to prepare special meals and persuaded me to eat. We are healthy now and so grateful to VMM for educating us, it saved our lives"

Swami found taking 6 months of TB medicine on top of his daily HIV treatment gruelling, but the hardest thing to deal with was how people treated him and his sister.

"First, my aunt decided that she would rather leave her husband than live with us. Then everyone at school,

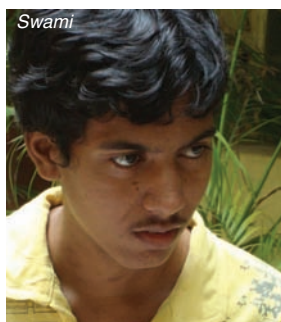
including the teachers, shunned us. The other children wouldn't play with me and the staff made me eat my dinner away from the others. Both Vennela and I have found this very difficult."

Swami is doing what he can to raise awareness of TB and HIV in school because he doesn't want other children to have to suffer the way he and his sister did.

"In 2008 VMM suggested I help them set up a School Support Group, and I was selected as leader for our group. I take this responsibility seriously, as it is an opportunity for me to share my story and to educate students and teachers about TB and HIV, and prevent discrimination in schools. Last year I was also very proud to be selected to talk about my experiences, and those of other young people with HIV, to the Director General of the National Aids Control Organisation."

Swami hopes to become an accountant and earn enough money to support his sister and uncle. Despite all he has been through, Swami is very positive about the future. He knows that there is life and hope if TB can be identified and treated.

"In future I want to set up an organisation like VMM and support social services for children living with HIV and TB. I will be able to motivate the children to work hard at school and encourage them. I will say 'look at me, I live with HIV and I have had TB too, but I have not let it hold me back'.



VMM's kids club where the children taught me how to play the TB/HIV snakes and ladders.

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