

Walabai battled despair and discrimination after her husband died of AIDS and she was found to be HIV–positive. But she learnt to cope: “I would like to tell all persons who are positive that they must live well and not get depressed.”

My name is Walabai and my original village was near Chandoli in Shirala taluka of Sangli district. My parents were agricultural labourers. They had to move because the site was chosen for the construction of a dam. They were allotted land in Kurlup village in Walwa taluka where I was born. We were four of us in the family, two sisters and my parents.

My father died when I was three years old. I had studied up to the sixth standard but financial problems put an end to my studies and I started working on the farm with my mother. I was married when I was 12 years old. My husband worked in Mumbai and I stayed with my mother who was ill with asthma so the responsibility of running the household fell on my shoulders. My husband visited me every six months. I became pregnant and within four years of marriage I had three children, two girls and one boy.

In 1986 I lost my mother. My husband also stopped sending money from Mumbai so I started working outside, in the cotton factory, in the fields as a labourer and for some time even filling trucks with sand from the river.

In 1998 my husband fell ill and returned to the village. He had TB. His mouth was full of small pus–filled bubbles. We started medicine for him but his family insisted that the problem was caused because the family god was displeased so we spent a lot of money in appeasing the gods – goat sacrifice among many other rituals, and witch doctors.

When my mother was ill, a doctor used to come home to give her an injection every day. He had insisted that I sterilise the needle for him and when I told him I thought this was unnecessary, he told me about HIV/AIDS and described the symptoms.

When my husband came back to the village because of his illness, I noticed that he had lost weight and had a persistent cough and breathlessness. I was very conscious of the symptoms so I took him to the same doctor, who asked for his blood to be tested. My heart was beating fast and I was scared but my husband was unconcerned. He was drinking heavily and was addicted to gutka.

In June 1999 he was tested for HIV at a lab in Chikurde. The lab asked us to come back in two days. Those two days were the most frightening. I had no idea what fate had in store for me. We took the report to Dr Gavli who told us that my husband was HIV–positive. I felt a deep darkness envelop me and was terrified of the future. The doctor was very kind and helped me to stand firm and face this disaster. As people came to know about my husband’s status they started keeping away from us but I stood firm and decided to take care of him.

My husband refused to have sex with me, but I felt he would be miserable so I continued to have sex with him. No one told me that this was one route of transmission for HIV. I had no idea that it was sexually transmitted.

Meanwhile, I mortgaged our land with the Warna Shakari Bank, Warnanagar, for Rs 50,000 to

pay for the medication and treatment. In 2001 the money got over and he fell critically ill. I got him admitted to the Sangli civil hospital. But the doctors soon told me to take him home because he had stopped responding to the treatment. He died within eight days of coming home.

Relatives who came for my husband's funeral insisted that all of us get tested for HIV. The children were all negative but my report was reactive for HIV. I was ecstatic that all my children were negative. I decided to live for them and I felt I should dedicate all my life to their welfare.

I earn Rs 3600 per month by running a small canteen for five teachers who live and work here in the local school. I have been able to return Rs 87,000 of the Rs 50,000 loan that had doubled to Rs 100,000 when my husband died. The land is being tilled by a person who gives me a share of the crop as is the local practice.

Recently I was able to counsel a couple who are both HIV-positive to take antiretroviral treatment (ART) from the civil hospital. I will also have to start ART soon as my tests show that I will have to do so in a while.

I would like to tell all persons who are positive that they must live well and not get depressed. Use medications thoughtfully. Live with strength and don't beg for anything. Do not hide your status from persons like doctors. They may be able to help you.

After her husband's death from AIDS, Shakuntala had to latch on to anyone who would give her some protection. "Fate, drought, no work and no support, all are responsible for the mess my life has become," she says.

My name is Shakuntala. I live with my mother in Gaurgaon village. My father and brother work in Mumbai and I have two married sisters. My father would come home twice a year but after his wife left him my brother stopped coming to the village. I studied up to the fourth standard but could not study further, though I wanted to, because of financial reasons. I started working in the fields after this. When I was 16, I was married off to a truck driver. This was in December 2002.

When I went to my husband's house I learnt that he was a widower, his first wife had died during childbirth. My husband was out of the house for eight to ten days at a stretch. I got pregnant almost immediately after marriage. My husband was ill very often and finally stopped going to work. I was used to doing work so I started going out to work as an agricultural labourer. On days when my husband felt better he also went to work. This went on for six to eight months.

My mother took me home after the seventh month, as is the practice in these parts. My husband was ill so I refused to go home, but he insisted I should go, so I did. The following month I got a call from my in-laws to say that my husband was seriously ill. I went home to find that he was on his deathbed. He died soon after. The people who attended the funeral were discussing that he died of AIDS. I heard of AIDS for the first time then.

I was upset about his death but was scared for myself too. I was depressed and after all the rituals were over I went home to my mother. My father and brother did not know anything about this but my mother was very supportive.

I attended the clinic at the PHC and was under their guidance. There I heard about Sangram and that they give information about HIV/AIDS. My mother and I waited till the hospital was empty and then went to meet the Sangram health worker. I told the counsellor all the details of my husband's death. I was told to continue medicines in the PHC but that I would have to go to the Sangli civil hospital for my delivery. I was told that if I take some medicine, the chances of my child not contracting HIV were high.

But Dr Sonawale of the Mangarde PHC told me that no such medicine existed. Still, I did not take a chance and went to the Sangli civil hospital for my delivery. I was introduced to Dr Bokare by a social worker from Sangram. Tests showed that I am HIV-positive. As soon as the labour pains started I was given a tablet and after some time I delivered a baby boy. The baby was also given some syrup. I was given counselling regarding breast-feeding my baby and other information about the care of the baby. Four days later I was discharged and went back to Gaurgaon.

I took my baby every month for its vaccinations to the nearest primary health centre in Manjarde. We had no money so we used to walk to Manjarde from Gaurgaon, a distance of about eight kilometres. Gaurgaon is in a drought-prone area and we have very little rain and consequently no work.

I would also go to Tasgaon sometimes. On the way I met a man called Ravindra. I was very attracted to him. One day my mother and I were walking down from Manjarde to Gaurgaon when we met Ravindra and I introduced him to my mother. He dropped us home and had tea with us. When he left he gave us some money.

He started coming regularly after that. He was married twice and had three children. But he said he could provide for all of us. The neighbours did not like him visiting us so often. They were rude and abusive, so I left Gaurgaon and went to stay in Tasgaon.

After a few months Ravindra came to know that my husband had died of AIDS. He insisted that we both be tested. I was pregnant with his child. Both of us tested positive. Ravindra left me immediately after this and I returned to Gaurgaon to my mother. I decided to abort the child and had a medical termination of pregnancy. In the meantime my mother-in-law came and took my son away. Ravindra had been taking care of all our expenses but now we were back to begging for food.

Starvation drove me to look for another benefactor. My son at least was being taken care of by his paternal family. I met a hamal (labourer) in the market yard and decided to ask him to marry me. Marriage at least meant some security for me. We now live together in a village five kilometres from Tasgaon. Fate, drought, no work and no support, all are responsible for the mess my life has become.

Married at the age of 14, Manisha found out after the death of her husband from AIDS that she too was infected. Her in-laws refused to spend money on her treatment, and the doctor at the local hospital refused to operate on a tumour because she was HIV-positive.

My name is Manisha. I am from Mankarwadi village in Shirala taluka. Most of the men in this region work in Mumbai. When I was 14, I was married to a man called Ananda. I had no idea what it meant to be married but I was unable to say anything to my parents. I knew nothing about the boy but when I came to my new home I was shocked to discover that he was already married.

My husband told me that I was the second wife and that both of us had equal rights over him. His parents also lived with us. My husband was a taxi driver, he left home early and returned very late. I also discovered that he was an alcoholic and was addicted to tobacco.

Within the first year of our marriage I became pregnant. I delivered a baby boy. His name is Tejas. At about the same time my husband started falling ill. Just simple fever and weakness but slowly the frequency increased. He then got Nagin (Herpes zoster) and he developed some tumours in the neck region. We took him to the government hospital. I was not allowed to enter the doctor's cabin. I kept asking him why he fell ill so often but he brushed me aside and said it was because of work pressure. But when he fell critically ill, I was told he had AIDS.

I wanted to get my blood tested then but circumstances were such that I just was unable to do so. We had already mortgaged all our land during his illness and treatment. He just did not improve and died in 2001, four months after I was told he had AIDS. After he died, both my son and I got tested for HIV. I was shocked when I heard the result. I was hoping I would not test positive. Fortunately, my son is negative for HIV. My husband's first wife refused to get tested and she remained with my in-laws. They even took my son away from me. They thought they could contract HIV by living with me.

In the meantime I met the arogya sevika who came and counselled the family about transmission modes and after some time the family accepted me back and we started living together. But my in-laws refused to spend money on my treatment. They spent so much money on their son when he was ill and I took care of him also, but they did not want to spend for my treatment.

I had three operations to remove tumours in my stomach. Two were at a private hospital, but I went to a government hospital the third time. The doctor there refused to do the operation when he found out that I was HIV-positive. He sent me back home. He even accused me of withholding information that I was HIV-positive. I was scared to tell him that I was positive because he would not operate on the tumour, and that's what happened.

During this problem with the government hospital I met a man who was very helpful and understanding. He just could not believe that I was HIV-positive. He got my blood test done once again and only then accepted the fact that I was HIV-positive. He refused to leave me and we now have a relationship but we use condoms. I trust him and I think he will take care of me till the end. I take care of the house myself. I do domestic work and agricultural work.

I know about ART but I feel that if the civil hospital does not continue the free supply then it will be very difficult for me to buy the medication. I have not yet registered for ART because of this reason. I am not ill, I may register if I fall ill.

Sold into prostitution at the age of 14, Anita was unable to negotiate for safe sex, and was diagnosed as HIV-positive. Undergoing treatment now, she also counsels others about how to live with HIV/AIDS.

My name is Anita and I live in Gokulnagar, Sangli. I was born here. My mother was a prostitute and I studied in a municipal school up to the third standard. When I was very young my mother took me to Saundatti and dedicated me to the goddess Yellamma. I had no idea why they do this ceremony. I stopped going to school. Life was fun then. I learnt to ride a bicycle and became very tomboyish. When I turned 11 and started my menstrual periods my mother told me to stop roaming about and to get ready to start dhanda (business).

At the age of 14 I wanted to get married but was told that devadasis cannot get married to men. I then started dhanda at the age of 14. My friends who were older devadasis taught me about sex and business. I was scared in the beginning but slowly I settled down. Those days Nirodh (condom) was not used much. But married men and some educated types used condoms. I once asked a man why he used a condom and he said that he was married and if he contracted a sexually transmitted disease he would pass it on to his wife and he did not want that. One of my regular clients fell in love with me and I stayed with him for two years.

A social worker from the NGO Sangram, Meena, came to our community and told us about issues of HIV/AIDS and STD. She also trained us about our rights. We started using condoms with all our clients. But I was unable to use a condom with my malak (regular/ husband), and when I got pregnant, I decided to keep the baby. I was taken to the civil hospital for tests and was found to be HIV-positive. This did not disturb me, I was overjoyed that I was pregnant.

When I was in the ninth month my blood pressure shot up and the doctors suggested that I have a caesarian section. Before the delivery I was given Nevrapine and I gave birth to a baby girl. When she was three months old she developed pneumonia and died. I was devastated. I stopped doing dhanda.

When I started loosing weight Meena sent me to Pune to Dr Vinay Kulkari who got all the tests done and started me on ART. I had to stop drinking alcohol and chewing tobacco, which was very difficult, but I have managed to do so.

However, I found it very difficult to continue with the treatment. I had stopped business totally and just could not pay for the ART, so I stopped the ART for two months. Then Sangram arranged for me to start the treatment again and when the ART roll out in the civil hospital was announced, I enrolled in the programme and am now getting treatment from the civil hospital and have been on ART since March 2005. Opportunistic infections have stopped so I feel healthy and am able to do routine work.

When I was diagnosed HIV–positive my family rallied around me and took great care of me. I work with Sangram now and help others who are positive. Prevention should be given importance, so we work hard to help women to talk to their malaks to use condoms.

I have one suggestion for people who are positive. Stop drinking and chewing tobacco and take care of yourself. You can continue to work and contribute to society as I am doing.

Sangram, a non–government organisation has worked with sex workers in Sangli, Maharashtra, since 1992. In 1996, the programme broadened into a collective of women sex workers against injustice called Veshya Anyay Mukti Parsishad (VAMP).

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