



# PLUS

## Case studies February 2010

### Pune

- Doctors/ hospitals
- Confidentiality
- cost of 2<sup>nd</sup> line
- cost of bus fares
- stigma from family
- stigma from community

“He needs to travel every month from Pune to Mumbai which costs him 600 rupees. This is a large portion of the wage he makes as a tailor and he finds that he is often going without adequate food. This financial burden is causing him stress and anxiety which in turn can affect his health”.

Bhausahab is a 29 year old man living in the city of Pune, he is living with HIV.

Bhausahab agreed to share some of his experiences of living with the HIV virus in modern India.

Bhausahab was married in 2003, he became ill about 7 months after and was admitted to a private hospital. The hospital suggested that he be tested for HIV as they couldn't diagnose what the problem was. He was tested and the test came back positive.

The Doctor did not tell him that he was HIV positive immediately, he first told his brother and his brother then told his wife. He was then informed by them. His wife was tested and her test came back negative. He was advised by the hospital that he should never have sex again, he wasn't given any information about safe sex. The hospital didn't give him a CD4 test before issuing him with medication, this would have indicated whether or not he needed to be medicated and the type of medication he needed. They gave him some medicine and told him that he would need to take it twice a day, they also took a lot of money from him for the services. He paid the money and didn't ask anymore questions as he did not know anything about HIV at this point. Bhausahab was discharged from the hospital shortly after being issued with medication. He was collecting his medicine every month and paying 2500 rupees.

Bhausahab's family reacted badly to his HIV status, they acted as if they hated him. They kept all of his belongings separate and ordered that he sleep in a different room. His wife was supportive however and did not act in the same way as the rest of the family.

Bhausahab is a tailor by trade, but after the community found out that he was HIV positive they would no longer come to his shop. He could no longer support himself and his wife, or contribute to the family financially. His family had to support him, and they did so begrudgingly.

Bhausahab first made contact with NMP+ after he was given information by a compassionate community member, he went to visit one of their outlet centres, the Pune Positive Living Centre. He was given information and advice about HIV.

Shortly after he decided to move to Pune with his wife as it was too much for him to stay in the family home where he was made to feel like an outcast. He continued to be supported

by NMP+ in Pune. They advised him that he should be able to get the medication he was on for free. He was given regular counselling and practical support and he began to feel as though he was worth something again. Bhausahab experienced a long overdue sense of belonging and acceptance while receiving regular front line services from NMP+. In Bhausahab's case it was a challenge for him to get 2nd line treatment simply because he had been paying for his first line treatment. NMP+ ran a campaign which had the focus of gaining free 2nd line treatment for everyone who required it. This campaign helped Bhausahab to gain free second line treatment even though he had been paying for his first line treatment (usually if you pay for your first line treatment you cannot have free 2nd line treatment).

He needs to travel every month from Pune to Mumbai which costs him 600 rupees. This is a large portion of the wage he makes as a tailor and he finds that he is often going without adequate food. This financial burden is causing him stress and anxiety which in turn can affect his health.

Bhausahab is still taking 2nd line treatment which he is getting free of charge, however He wants to open his own tailoring business but is being discouraged by his family as he sometimes gets ill and they feel it would be a waste of time. He only speaks to his family on the telephone these days and they still treat him with disrespect. His wife left him shortly after they arrived in Pune. He hopes that he can one day open his own business but he will need to save some money before he can do that and at the moment due to the amount he spends travelling to get his medication, this is just not possible. He is grateful for the support he continues to receive from NMP+.

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## Pune

- cost of bus fares
- non disclosure
- stigma

“These travel costs mean that he has to borrow money from neighbours and family members which means he now owes more than he makes and just cannot keep up with the costs. These costs are causing him and his family stress and anxiety as it is affecting the money they have for food and other essentials”

Prabhaker is 42 years old and living in Pune. Prabhaker, his wife (36), his Son (16) and his daughter (14) are all living with HIV. He agreed to share some of his own, and some of his family members experiences of living with HIV.

Prabhaker knew he had HIV but initially kept it from his wife as he knew that it would cause problems with family, work and his community. His wife began to have health problems in 1995 and was admitted to a private hospital, the Doctor suggested that she have a HIV test and she tested positive. It was then suggested by the doctor that Prabhaker and his two children also be tested, they all came back positive.

Prabhaker's family reacted well to his and the rest of his family's HIV status as his father had some prior knowledge of HIV. His father suggested that Prabhaker look after his own and his family's health by eating well, doing meditation and praying. His mother had previously died of cancer. Prabhaker's brother reacted negatively to the news that him and his family members were HIV positive, he ordered that they live in a separate room and that they touch only their own food, plates, cups and other belongings. Prabhaker explained that his brother seemed very angry with the family and that the atmosphere was full of tension and hatred. In the end his brother went to live somewhere else as he didn't

want to be near Prabhaker or his wife and children.

Nobody in the community knew about the family's HIV status as they decided they would keep it a secret rather than face exclusion from the community. His two children are in school and he doesn't want the school to know about their status as he fears their reaction. He works for himself as a farmer and so far his business has not been affected.

In 1997 Prabhaker was introduced to an NGO with some expertise in the area of HIV. His wife began taking medication after getting advice and having a CD4 test. In 2000 Prabhaker began taking first line medication. The NGO really helped the family to understand more about the HIV virus, the CD4 tests and the medication needed to manage the virus.

In 2003 Prabhaker disclosed to his wife that he knew about his HIV status before she became ill. Prabhaker explains that he has several reasons why he chose not to disclose the fact that he had HIV earlier to his wife. At the time she was suffering from epilepsy and he did not want her to feel additional stress at his HIV status. At the same time his mother was also suffering from cancer which was putting strain on the family. Prabhaker also feels that the social stigma that was attached to HIV made it a difficult thing to admit to himself as he knew that he would be discriminated against and perhaps lose his family and farm. Non disclosure of HIV in India is common as sufferers are aware of the huge impact it can have on their lives, this means that people living with HIV often don't seek help or advice and can end up infecting their spouses and children.

It is only in the last six months that Prabhaker has been accessing services provided by NMP+. So far they have received regular counselling sessions and been given up to date information about people living with HIV, the different medications available and when and how they should be taken. They have also been educated about the rights of people living with HIV. NMP+ also helped to advocate for access to 2<sup>nd</sup> line treatment for his wife.

The main practical problem that Prabhaker is facing at the moment is the collection of the medication. He needs to make 3 trips a month to collect medication for him, his son and his wife (his daughter is not taking medication at the moment as it is not necessary). He travels with his wife once a month to Mumbai which costs a total of 880 rupees and then twice within Pune to collect his and his son's medication at a cost of 400 rupees. These travel costs mean that he has to borrow money from neighbours and family members which means he now owes more than he makes and just cannot keep up with the costs. These costs are causing him and his family stress and anxiety as it is affecting the money they have for food and other essentials. Prabhaker tries not to think about the future as to him it seems bleak with more costs and illness. He is just trying to live in the present. He feels more accepted since he has been receiving services from NMP+ as he sees that he is not alone in his plight and has a community who can empathise and offer real compassion and understanding.

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## Pune

- Stigma
- doctors/hospitals
- quack medicine
- work

Satyabhama is a 33 year old woman living in Pune. She is living with HIV and wanted to share some of her experiences.

"The boss on the farm and the other workers would not talk to her apart from to ask her about HIV, she was told to keep her lunch in another area as if it may somehow affect the other lunches with the virus. Satyabhama was also told that she couldn't drink out of the drinking water tap and would often be thirsty during working hours".

In 2000 Satyabhama's husband was taken ill and had to be hospitalised. The Doctors at the hospital could not find the cause of his illness. A family friend suggested that they change the hospital so that they could find out what was wrong with him. In the new hospital they asked if he had been tested for HIV in the past, and the answer was no. It was suggested that he be tested. His results came back positive. It was then suggested that Satyabhama be tested too as he may have passed on the virus. Her test also came back positive.

They were in a private hospital and the bill for their care was quite high so they were not immediately stigmatised in the hospital as HIV sufferers often are in India. Her husband recovered and he was discharged. They were given some medication and told to take it everyday but they were not given further advice and they did not always take the medication. The hospital did not do the CD4 test which is essential to determine whether the affected person needs to take medication and the amount they need to take.

Satyabhama's immediate family had some knowledge of HIV as another family member was living with the virus. The family were supportive of them and wanted to remain in contact. The extended family on the other hand were not supportive and they didn't want any contact with them and said that neither Satyabhama or her husband were welcome in their homes. They also encouraged the local children not to play with Satyabhama's two children.

Satyabhama and her family moved to another district so that they could have a fresh start and have their own space. They had also made contact with a relative living in this district who knew some Doctors in Kerala who they were informed could cure the HIV virus. They were anxious to be near this relative so that he could help them to get the treatment from Kerala. They got some of the medication on one occasion by post and said that they felt good when they took it but they were not sure what the medication was and if it helped with their condition.

At this time Satyabhama's husband was too ill to work so she went to work on a local farm. She found the situation at work difficult as she was discriminated against because of her HIV status. The boss on the farm and the other workers would not talk to her apart from to ask her about HIV, she was told to keep her lunch in another area as if it may somehow affect the other lunches with the virus. Satyabhama was also told that she couldn't drink out of the drinking water tap and would often be thirsty during working hours.

About 8 months after his HIV results Satyabhama's husband died. This had a big impact on her and made her worry for herself and her family's future. Satyabhama again decided to move on as there were too many bad memories in the home they had been living in as a family. They moved to Pune and Satyabhama rented a room and washed clothes to earn money. One day by chance NMP+, who were conducting a health survey, came to her house to talk about general health and the topic of HIV. She disclosed to the worker, from the Pathway Project at NMP+, that she was HIV positive and that her husband had recently died of AIDS. Satyabhama was immediately linked in with the services which were long overdue to her.. She was allocated to a peer counsellor and had a CD4 test. She was given emotional and practical support. NMP+ explained how to access medication and how to take it correctly so that it would be effective. Satyabhama is now regularly taking her medication and feels healthy.

Satyabhama's two children both tested negative but she still had concerns about their welfare. Before she had been helped by NMP+ she took her son to a hostel so that he could get a better education. When he was at the hostel he was beaten very badly and not given any medical assistance. NMP+ helped her to get him some treatment in the hospital

and also supported Satyabhama in making a complaint to the police which was then investigated. She feels that without NMP+ she wouldn't have had the personal strength to fight for justice for her son.

Satyabhama is currently working in a paid role for NMP+ and really enjoys using her personal knowledge and experience to help others. She feels that her life has improved since she was introduced to NMP+ and that she has lots more self worth as she feels accepted as part of a community. Satyabhama would like to see more acceptance from society, and for people living with HIV to be seen as humans before they are seen for their HIV status. She believes that education about HIV would help to change the way society thinks about people living with the virus. Satyabhama had many sleepless nights worrying that her daughter would not marry because of her status, but she is now a proud and happy grandmother and all of her family feel they have a bright future.

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