



WHEN I CAME TO
KNOW ABOUT IT...

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IT...

For those parents who still haven't
told their children...

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PRAYAS

Initiatives in Health, Energy,
Learning and Parenthood.

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The Health group of Prayas works in the field of HIV AIDS. The work in this field encompasses several aspects like treatment provision to HIV infected individuals, services for prevention of new infections, services for prevention of mother child transmission of HIV, counseling support to HIV infected individuals for psychological and behavioural issues. While working in this field, we draw our inspiration from our patients, which include adults and children alike.

Several children come to Amrita clinic at Prayas to seek treatment for HIV. Like any other children, even these children are full of life and energy. They are full of new ideas and may surprise you with simple yet clever solutions to seemingly complex issues. This booklet is a simple yet a very clever solution to a huge issue at hand.

This booklet narrates what the children experienced when they were disclosed about their HIV infection. We wish that this booklet reaches maximum number of parents and we hope their children are benefited.

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PREFACE

Many children living with HIV come to PRAYAS for their treatment. Most of these children have been infected at birth. Some of these children have now entered adolescence while some are older. With proper care and regular medication, these children are leading a normal, happy life.

While talking with these kids, we realized that though they are living happily and fulfilling their responsibilities in life, they still have many concerns while growing up with HIV.

Usually all adolescents face several questions while growing up. The complexity of the questions has increased for these adolescents living with HIV. It is necessary that we find answers to all the questions that arise. We mulled over the situation and with an objective of increasing the capacity of these children to face these questions, we decided to organize a workshop for the adolescents coming to PRAYAS.

Fifteen boys and girls participated in this workshop. With enthusiastic participation from everybody, the workshop was a success. A special bond was created amongst all of us because of the residential nature of the workshop. The children connected with each other instantly because of the common thread of HIV. Several issues were openly discussed in the workshop. During the workshop, some difficult questions were spelled out; we found answers to some questions, while some new questions also emerged through open dialogue. Some bitter memories of the past were revisited; but now each of them had the confidence that they were not alone. All of us were beautifully bonded by friendship. Even we started envisioning a brighter, better future filled with hope and support for all.

At the end of the workshop, the participants decided a name for this friend circle; '**So What!**' "We have HIV, so what! It is a fact. But we will live and have a splendid life."

The 'So what!' group started meeting regularly after the workshop. They decided that they would work for other HIV infected children. During one such meeting, the members of this group were discussing issues faced by the younger children coming to PRAYAS. The members were aware of these issues as they themselves had faced these issues in their earlier years.

Parents do not disclose the child's HIV status to the child till he or she is 10-12 years of age or even beyond. Many children are taking medication. They do visit the doctor regularly for their treatment, medication and blood tests. Till this age, the children can read and write well.

They are aware about what all is happening in their surroundings. They do have questions like why am I being given these medicines, why am I being brought to this clinic? They try to find answers to these questions by themselves as there is no possibility of asking anything about this to anybody. The parents are aware that they need to have a dialogue with their child. But in reality very few really do it. Children then start feeling lonely, "Nobody thinks what we are going through!" If they find out the truth later from their parents or from some random person, it can lead to a severe outburst.

The members of 'So What!' had an intense discussion about parents refusing to talk to children about their HIV status. They all shared their experiences surrounding their individual disclosures. They told that, 'children do get troubled after coming to know. But still, one needs to know. It is every child's right to know what is wrong with him/her.'

After spelling out the true state of affairs, they started thinking about the solution to this problem.

They said, 'We shall talk to the parents. We shall tell them what the child thinks about.'

The idea of compiling this booklet emerged from this concept.

When we spoke with the children while creating this booklet, we realized that these children have immense strength. Probably not many children of their age could do this. They were thinking beyond themselves. Very sincerely, they dared to look into their bitter pasts and narrate their stories with the objective that other children should not go through the harsh times they had to endure.

This booklet has real life disclosure stories of some of these children. These stories were narrated by the children themselves. Neha and Manik, members of PRAYAS helped them out to create this booklet. We have changed the names of the children in these stories to maintain confidentiality.

Should I share with you my personal feeling? These children from our 'So What!' group are very sweet. They have accepted HIV as a color in their life. They believe that for better survival, they need to make the biggest weakness in their life into their biggest strength. Thus, they have made HIV their strength and are living with great aspirations. I would sincerely request you to read their stories carefully, consider them and try to understand what they are trying to tell you!

Sanjeevani Kulkarni

Aditya

I am Aditya and.... What else can I say? I'm not really used to talking about myself, and I'm always unsure where to begin...

I finished my schooling and enrolled in a diploma course in civil engineering. Since getting my diploma, I have been working with a builder as a site in-charge. I have to supervise the work that is being carried out and ensure that it is going according to the plan.

I stay in the city of Pune with my mother. Since I have lived in the city all my life, all of my relatives and friends are here. I had decided when I was in school that I would pursue a diploma.

I did not like commerce and science was hard for me. Thus, the diploma was the only option.

Now, I spend most of my day working. I spend my free time mainly with friends or reading books.

I am not a person who spends lot of time thinking or introspecting. I live in the moment. I set small goals and tasks for myself and try achieving them.

I contracted herpes zoster when I was in seventh standard. That was the first time I visited Dr. Vinay Kulkarni with my mother. Eventually, my herpes was cured but my visits to Dr. Kulkarni continued. Visiting the clinic, reading to kill time while waiting for my turn in the hall, meeting the doctor, getting the check-up done, buying medicines, occasionally giving blood for testing; all of this became a routine.

By the time I started visiting Dr. Kulkarni, I was at an age where I could read and write well. The board outside the doctor's office said 'Skin specialist and HIV physician'. I had read that.

Initially, I paid no attention to the fact that the board had 'HIV' written on it. I was consulting him for my skin infection, for my herpes; at least that was what I thought.

However, when my visits to the doctor continued even after my herpes was cured, I became suspicious about the 'HIV' written on the board. I thought, "They test my blood often. This means there is something wrong with my blood." I was also on regular medication. Then I started noticing the posters and books displayed in the clinic and felt that I probably had HIV.

"How did I get this disease after all?", was the question that bothered me in the beginning. From whatever I had learnt in school, I knew that HIV is transmitted through blood. Then how did I get it? Did I get it when I was down with hepatitis as a young boy? I must have done something wrong to contract this HIV!

However, I did not stress about it much because of my attitude. I thought about HIV only when I visited the clinic at PRAYAS but forgot all about it when I was with friends.

I could not ask my mother any questions regarding this. On one or two occasions, I did try.

However, when I realized that she was avoiding the topic, I dropped the matter right then. I could never discuss this with the doctor as my mother was always around when we visited him. I did not know the doctor well, and in fact, I was a little scared of him. Anyway, I was unsure as to how to bring up the topic and even what to ask the doctor.

Now in this situation, all I had was myself. I was the one who would find answers to my questions and I was the one who would console myself.

My mother took me to PRAYAS to meet Sanjeevani madam once I finished with my tenth standard board exams. Sanjeevani madam told me about my HIV infection and it became clear that all of my doubts and fears were true.

Sanjeevani madam explained several things to me which answered several questions that I had had for a while. I had contracted HIV from my mother at birth.

A baby gets many things from his/her mother: looks, qualities, mannerisms, features, temperament, upbringing.... HIV can be one of these. If the mother is infected with HIV, sometimes the infection is transmitted to the baby. However, no mother has control over this....if she did she would have done everything in her capacity to protect her baby. Sanjeevani madam explained all these things to me.

She told me that if one takes the medicines properly and regularly, one could lead a normal life.

She also explained to me the different medicines and what they do in your body.

I asked her, 'Why me? Why did I get this infection?' I had not hurt anyone in my life, I had not wished bad upon anyone. Then why did I become a victim here? She explained to me giving an example of a road accident "Consider your case similar to an accident. You do not have HIV because you acted badly with somebody. It just happened and no one had any control over it."

While returning from PRAYAS my mother asked me if I was under any tension. I declined saying, "No, not much." That was the only time my mother spoke to me about HIV... not a word before or after....

When I listened from Sanjeevani madam about the HIV infection, I was not shocked, as I had been preparing myself for almost two years. However, this could not be the case for everyone.

Since I am quite tough, I could understand the situation and was able to comfort myself when required. One cannot expect that all children would react with this maturity on sudden disclosure of such a life-altering fact.

I think children should be informed of their infection gradually from the age of 10-12. Small bits of information at a time can help. However, it is indispensable to prepare them for the truth.

Thus, a truth this intense could be made somewhat palatable.

Parents should talk to their children. You can give them books to read about this issue; sometimes let them go to the doctor on their own. They should get the opportunity to ask questions. However, please remember that it may be a difficult task for the child to start a conversation and ask appropriate questions, so the doctor or counselor will have to take an initiative.

In any case, one thing is certain, the children should be told about their HIV. They are going to find out about it one day or the other. Even if we children are young, we can think, we can read and write, we can figure out that two and two equals four. Some shrewd children like me might come to know about their infection and make peace with it. All the same, some children may just explode in anger.

I also feel that doctor should do the final disclosure. Parents and relatives may not be able to explain it to the child as well as a doctor can. The doctor could explain giving some examples.

The child also feels satisfied if he/she understands and is given correct and truthful answers. A mother might not be able to explain it so clearly, as she herself might not know everything. In addition, no mother would feel comfortable telling her child that she is the reason for the disease the child has to bear for rest of his life; but she is completely helpless.

Anyway, one tablet in the morning and one tablet in the evening; that is what HIV is to me. I am not at all bothered by the thought of HIV when I am working or am with friends. I only think about it when I lie in bed at the end of the day. That is why I keep myself busy throughout the day with something or the other.

I am reminded of my illness when I have to go to PRAYAS to visit the doctor. However, I am not troubled by it anymore because now I am also reminded of all the friends that I have made at PRAYAS. I had participated in a workshop organized by PRAYAS. There I realized that I am not alone. There were several other children in a situation similar to mine. All the children who came for the workshop were infected with HIV. However I had listened that there are many HIV infected children like me, I was not convinced but when I met them, it changed my life. Now am not worried about the future any more. If so many children are living with HIV, I shall too!

This does not mean that all the questions in my mind have been answered. What would happen if I missed my medicines? How would I take my medication if I go out on a trip with my friends?

How should I respond to my friends nagging me about getting a girlfriend? If I really do meet a girl, how would I tell her about my condition? What reason could I give for not donating blood at a blood donation camp organized by the college? Many such questions arise in my mind. Now I know that I will not have to look for these answers alone. My friends at PRAYAS and the doctor are there with me!

Now I live with a peaceful heart and a free mind....

Aarya

I am Aarya and I am 20 years old. I stay with my parents. I have an elder sister, but she is married and stays in Nashik. Both my maternal and paternal uncles and aunts stay close by. All of them keep coming to my house every day. I love to be surrounded by people all the time; by my friends, when in college and by my relatives, when at home. Everybody refers to me as 'chatter box Aarya'.

I am currently pursuing my bachelor's degree in commerce. In the morning, I go to college. I come home in the afternoon around 2:30 and have lunch. Then sometimes I study, sometimes I watch T.V., or sometimes have a nap. In the evening, I have my tuitions. When I come home at night, I have dinner with my parents and then spend the remaining time chatting with my cousins. This is a typical day for me.

When in school, we were given information about different issues, other than the usual curricula. I particularly recollect one such session on HIV. They had told us what this disease was, how it was transmitted, and how it could be prevented. I thought I understood everything and had even tried to retain the information. However, it soon lost its importance and value as I thought it would never be applicable to me in any way.

But, I realized it very soon that HIV had become a part of my life, forever...

I had herpes zoster when I was very young. But it got cured pretty soon without much hassle. I again had an episode of herpes zoster in the summer vacation after my tenth standard exams.

However, this episode was intense and very painful. This was the first time I visited Dr. Vinay Kulkarni. At that time, I was around 15-16 years of age. The skin rash got subsided eventually still visiting the doctor did not suffice and we started visiting him routinely.

On one such visit, I overheard the conversation between my mother and the counselor at the clinic. The counselor was asking my mother if 'I knew anything about it'. I gathered some courage, went inside the room and directly asked the counselor, "What do you want or do not want me to know? What is it that I might not know?" The counselor could not see a way out of the situation and had to tell me that there was some problem with my blood. The information provided in school suddenly came back to me and I simply asked my mother, "Mom, do I have HIV?" The answer I got wasn't unexpected but was definitely shocking!

That day I cried my heart out in the clinic...But, as the initial shock wore off, I became very quiet once I reached home. The chatterbox turned into a hermit. I was subdued and unresponsive for more than a month. My routine was going on physically, but I was not involved in it mentally. Everyone else, who were unaware about this fact, were concerned about why suddenly I had gone so silent. However, I did not speak to anybody about this. My mother had instructed me to do so, "Do not say a word about this to anyone. People will not understand." Even if she had not instructed me, I would not have said a word to anyone.

What was I going to talk to people about? I myself knew so little about it!

Eventually I found out that both my parents had HIV too! I took up the responsibility of their medication, their visits to the doctor and all other things. My mother was always reluctant to go to the doctor. Every time I had to think of some new reason to persuade her and take her to the clinic.

I accepted HIV as an indivisible part of my life. Taking medicines became routine. I resumed my daily routine – college, class, friends, relatives, chatting, enjoying. Everything seemed normal as before. But this was very superficial. Internally, I felt shaken.

If I look back in time, all I can see is my loneliness. There was neither any companion nor anyone to talk to. I was all alone. Several questions came to my mind. 'Why did I get this disease? How did I get it? Will it get cured?'

As I entered my adolescence, I started feeling all the things any adolescent girl would feel. But I also had several concerns about those feelings. Should I talk to boys at all? If a boy asks for my friendship, how should I respond? Would I ever get married? Will that boy ever accept me? I am sure none of the other girls faced these questions.

I wasn't able to ask these questions to anybody. My parents were mute on the issue of HIV. I wasn't as troubled by HIV as I was by the pain I felt because of these unanswered questions and the loneliness.

Even today, after all these years, the state of my family remains the same. We still do not talk about HIV. The relation between my parents has deteriorated since the diagnosis of HIV. They are constantly irritated with each other. I have become a target for both and they simply vent this irritation on me.

I feel that they never really have given a thought to what I must be going through in this situation. In the last 4-5 years, they haven't even asked me how I was doing! I was feeling giddy lately. When I told my mother about this, she said it would pass. But she did not take me to see the doctor.

Is she not concerned about me at all? She does not care for me but constantly shows her annoyance towards me. "You do not study. You just sit at home and watch those Bollywood songs on T.V. all day long. You laugh too loudly. You speak too loudly. Your behavior is inappropriate for a girl of your age and so you are not allowed to go stay with any of our relatives."

I have not let HIV alter my life in any way. I have not given up education, neither have I secured less marks in any exam. I try and do the household chores as and when my routine permits. I take good care of my parents. I always inform my parents when I go out; where am I going and when I am

going to return. I am probably doing more than what is expected out of a 20-year-old girl.

Then why am I being treated in such a way?

Do other households treat their children in a similar way? Is there no communication between parents and children? Do parents feel that their responsibility ends if they provide food and shelter to their children? How do they fail to understand the difficulties that their child has to face because of HIV? How do they not think about what the child is going through, both physically and mentally? Let the children grow up on their own; let's not bother about how they do it or if they need any support! I think this is the attitude that parents have.

I feel that the analogy of 'cat drinking milk while keeping its eyes closed' would be well suited for this situation. The cat feels that if it cannot see the world, the world would not see it drinking the milk. Till the time the children do not ask any questions, do not broach the topic themselves, try and ignore them. Assume that there is no issue at all. Ignorance is bliss!

I feel that we kids are more mature than the 'wise' elders are. If we sense that our parents are getting uncomfortable because of our questions, we just keep mum. We take all the stress upon ourselves but see to it that our parents don't get stressed. But this does not mean that we do not have any questions. We want someone of our own, someone who cares for us, someone with whom we can talk. We are aware that parents may not have answers to all our questions. But we would at least have some peace of mind after sharing our concerns with them. And I am quite sure that this sharing would be mutually beneficial. Even parents would feel relaxed after sharing.

The truth, which I overheard that day, was bitter and stressful. I did not live a completely carefree life after that. But I feel fortunate that I found out at least

then, when I was still in school. I got time to prepare myself. The information provided in school was also very useful.

Had I not found about HIV when I did and the later it got, I would have built my own dream world like any other young adolescent girl. And then that dream world would have crashed mercilessly upon coming to know the harsh reality so late. The stress at that time would have been probably unbearable.

I met Reshma, my bestie, during the workshop organized by PRAYAS. Reshma is a girl of my age who also is living with HIV. We share everything with each other; our questions, our concerns, our views. We try and solve our questions together. Sometimes we find answers for each other. Some questions remain unanswered. But we are not stressed by these questions anymore. At least now, we have each other to talk to and to openly say, "I am being bothered by this question." The best part, this sharing is not limited to HIV alone.

Many of my concerns were resolved after this workshop and due to all the wonderful friends I met there. I do not have doubts about getting married, having 'boy' friends anymore. It is not that I have found answers to all my questions, but at least I am not uncomfortable any more. I still dream like any other girl. But I am more aware of HIV in my dreams. I do want to get married someday, but before that I need to become strong and independent.

I still think about all those children who are as yet unaware about their HIV status. Their parents have not informed them. The children cannot broach the topic, as they do not have a conducive environment. My situation was and is no different. However, I do not feel that all others should face it too. This is the reason that I have openly narrated my story to you.

I have my friends and the people at PRAYAS with me. Probably you are the only person accessible to your children. Please talk to them, inform them about their condition. And do not stop there, try and continue the

conversation. After disclosing to them ask them if they have any questions. You can provide them with some books giving information about HIV. Still if the need be, PRAYAS is always there to provide any kind of support. Please embrace HIV, accept it and give your child the opportunity to embrace it too. So let's do it!

Dheeraj

My name is Dheeraj. I am 20 years old. I live with my mother and two elder brothers. I dropped out of school in tenth standard. But later, I completed twelfth standard externally and I am currently pursuing my bachelor's degree in commerce.

Being the youngest child, and my father's favorite, I was pampered a lot. However, I had to work equally along with my brothers. When I was young, we had a small business of providing lunch to office goers. My mother used to prepare the food and the job of dropping off these tiffins to their respective owners was delegated to me. I used to happily do this on my bicycle. As I grew older, I took up many odd jobs. Currently, I am responsible for managing a small hotel.

My day usually starts like this. I get up early in the morning and go to the gym; I spend the rest of the day working. I hardly find time to do anything else during the week. On a holiday, I go out with friends or sometimes go for a long, refreshing ride on my bike. If you see my life, I am doing what any other boy of my age would do. I am just like anyone else!

However, I always feel that it would have been better if I had done some things differently in my life. My father had HIV. My mother got HIV from my father and it was transmitted to me from my mother. My father died within one year of my HIV diagnosis. But the last phase of his life was just horrible for him, and went badly for me as well.

I absolutely loved my father and I was his favorite amongst his three children. I was aware that my father had HIV even before my diagnosis, yet it hardly made any sense to me. But when I found out that he had given this disease to me, my feelings for him changed dramatically. My hatred for him knew no

bounds. I constantly felt angry with him and I vented it out on him on several occasions.

Earlier, whenever my father was at home, both of us used to eat out of the same plate. This stopped later. I could not bear to be with him in the same room, let alone eating with him out of the same plate. I behaved very badly with him. And now I repent it....

The opportunity has been lost. My father is gone; he will never come back, and I will never be able to rectify my mistakes. I will bear this guilt forever. In retrospect, I feel that these mistakes could have been avoided had some things occurred differently.

I was always a sick baby. I was taken to several medical facilities but with no positive results.

We heard about Dr. Vinay Kulkarni when I was in seventh standard. My treatment started immediately after we visited Dr. Kulkarni. That time itself he informed me about my HIV. He said, "You have HIV, but do not get stressed by it. Everything will be fine if you take your medicines regularly." I felt that HIV was just like any other disease, which we get frequently, like cold, cough or fever. I had heard about HIV being prevalent in the community. I had seen some commercials about it. However, I started understanding it in its true essence only as I grew older. When I understood the disease in its entirety, it felt like my mind was literally falling apart into a thousand pieces.

Till now neither have I ever spoken about this with anyone in my family nor have any of my family members spoken with me about this. My conversation has always been with myself.....chatting, discussing, fighting, all with myself! My mother also never opened up freely to me. Perhaps she did not know much or she avoided it because it reminded her of my father, I know not for sure.

I was bothered by a lot of questions. What will happen to me? How long will I survive? Will this illness go when I grow up? Or will I have a very short life? Why did 'I' get this disease? Why should I continue to live if I have this disease? and many more. I was extremely stressed by these questions. I used to constantly think about these questions and sulk. I used to feel like crying all the time. I was in a constant state of fury. I had turned into this mean guy. I used to fight with my family and used to treat them in an unkind way.

I don't remember how, but during this period I found out that my mother was infected with HIV too! Under normal circumstances, one would feel bad about it. But I did not feel anything about it. She should have what she had given to me! Wasn't it fair?

The way I looked, the way I behaved was simply awful. It feels weird even to think about it now.

I lost my friends because of my behavior. And eventually I dropped out of school. If you want to stay in society, you have to adjust to its tune. I could never tune in!

Nobody ever said anything to me about my behavior; they did not ask me about dropping out of school either. My family members simply tolerated my mean behavior, probably thinking that HIV was the reason for it. They never forbade me from doing anything, or scolded me for my inappropriate conduct. They probably sympathized with me and left it to fate. But I did not want their sympathy. My stress increased manifold due to this sympathy.

Regular visits to the doctor and the medicines prescribed, improved my health. But the restrictions did not end. The counselors at PRAYAS spoke with me at each visit, "Take the medication regularly. Do not miss even a single dose. And they have to be taken on time too. Do not eat roadside food and always drink boiled water."

I was angered by these instructions. Why was 'I' made to follow them? I wanted to enjoy like any other kid. I wanted to indulge in tempting roadside food!

As my health improved further, I felt like breaking off these shackles. I did not want to take the medicines. 'I am no longer sick. I feel better. Then why should I take these medicines.' Slowly I started avoiding taking them. I started throwing away the medicines given by my mother or my brothers. Even if I remembered to take them, I pretended as if it never occurred to me.

Sometimes I took the medicines for a few days, and then stopped suddenly.

I started falling sick again. This time, the doctor did a few extra tests and told me that the medicines that I was taking previously were not working anymore. The virus in my body had developed a resistance to these and thus I would now require different medication. I was thus started on second line medication and my health improved again.

Improvement in my health made me realize that the doctor and counselors were telling me something of immense importance. Regularity in taking medicines was crucial. I started paying attention to my medication schedule and started taking them timely and regularly. Now my health is just fine.

I always felt that nobody should be able to make out that I have HIV, merely by looking at me."

If others dress well, why shouldn't I, just because I have HIV!" There was no reason to do that. I needed to not only dress well but to also look smart. Nobody should feel that I am deficient in something.

I started eating good food and exercising regularly. I started caring for my health more. I feel fortunate that I realized this at least then. If I had remained adamant and ignored the doctor's advice, I probably wouldn't have been alive to tell you my story. I feel that only taking medicines never helps. One needs to take care of all the supporting aspects as well.

I did not know the importance of exercise, medication, balanced diet when I was young. I used to feel: Why do you need to take medicines? Why should 'I' take medicines? Why do I have to take them daily and perhaps forever? What will happen if I discontinue? I did not know anybody who would answer my questions. I could not ask these questions to anyone. Nobody approached me to talk to me about this. There were counselors at PRAYAS who used to talk to me. But I did not feel comfortable talking with them; I did not know them well, they were strangers to me. I also did not know how I should talk to them. What would I ask? What would they think about me if I really shared what I was going through? Would they consider me foolish?' It was all very difficult.

The information, which I had gathered by hearsay, had created fear in my mind about HIV. My mind had become numb and there was no constructive thought process. If somebody I loved and trusted had told me about HIV sensitively, my fear about the disease would have passed. I am not justifying my behavior in any way, but instead of tolerating my rude behavior and sympathizing with me; my family members should have reprimanded me. They could have also shown some support, should have said some encouraging words. I did not understand that my behavior was wrong, probably because I was too young to understand it. It was a reflex reaction to the situation at hand. Most of the times, even adults fail to deal with HIV upfront and this definitely stands true in my case. The older members in the family should be able to deal with difficult situations and should be able to see what effects these are having on their near and dear ones.

Children should be informed about HIV when they are still young. One must ensure that children do not have any misconceptions about it. I was ill-informed and thus my knowledge about HIV was minimal. I used to feel that there is no cure for this disease and I am going to die soon. At that age, I actually did not understand what dying was or what living meant. But I had

seen my father die. I never wanted an ugly death like his. I used to be agitated at the thought of a painful death and vented out that anger on my family members.

In our culture, young children are adored and cared for. But they are just left out when a difficult situation arises, thinking, 'What will they understand? They are too young.' I feel that other children should not face the hard circumstances I had to face. They should not commit the mistakes I committed. The burden of those mistakes is too heavy to carry along all your life. And in this case, you do not get a second chance to rectify your mistakes. Most of the times, the opportunity has been lost.

Family members who are close to the child, with whom the child shares a good rapport, should disclose the true facts of the disease. If not, then help of a professional counselor could be taken.

The dialogue should be continued even after disclosure and it should be ensured that all of the child's questions are answered appropriately. The child should be told in such a way that s/he does not feel that something extremely serious has happened or the situation is unmanageable.

This does not mean that the child is given fallacious information. The child should not feel that his/her life has come to an end because of HIV.

I was disclosed when I was in seventh standard. The impression I formed at that time was horrific. It was unnecessary and false. But there was no one around me to rectify it. However, I still feel that it was better in some ways that I found out at that age. As the child gets older it becomes more and more difficult to hide it; rather it becomes impossible to hide it. The truth will find its way to the child. The effects can be ugly if the child finds out from other sources. If one thinks about it, one can see that my parents did not hide anything from me, but they also never told me anything about HIV concretely. They were unable to determine my intellectual ability to understand the

situation and deal with it and thus never told me anything. We did not share an open and free dialogue with each other. Parents and children should ideally share an open channel of communication.

Even the counsellor should think about the method in which HIV disclosure should be done. I believe children would not feel comfortable if they are taken to a closed space to talk about this.

They may feel overwhelmed by such a restricting space. They may feel that the fact that the

counsellor has brought me to such a place means there is something very serious going on. The atmosphere should be cheerful and positive. Several children facing the same issue can come together for healthy discussions. I feel that mere 'words of wisdom' from the elders would not help. Only children coming together also would not suffice. There should be something both encouraging and supportive. Thus, experiences of peers and interpretations of those experiences from elders would be the ideal combination.

For the past two years, along with managing my hotel, I have been involved with an NGO. This NGO works in the area of HIV/AIDS. Manik dada, counselor from PRAYAS sent me to this organization. I started getting a lot of information about HIV after joining this organization and I started meeting many HIV infected individuals coming here. That was the time I realized, 'these people are coming here for so many years and they are leading such normal lives. If they can do it, why can't I?' I felt that I was unnecessarily fussing about this disease. It was nothing so serious. I started calming down. The feeling of dejection started transforming to constructive thoughts. My behavior changed. I now care more for my mother.

In 2010, PRAYAS had organized a workshop. Several adolescents like me had participated in that workshop and the most important thing was that we all had HIV. It was very easy for us to connect with each other due to the

common thread of HIV. When you talk to a counselor, you discuss only your case, which is at hand. This was not the case in this workshop. All of us had HIV, but all of us were facing different situations. The peers were narrating their experiences and the facilitators were explaining the meaning and the essence of these narratives. The ways of facilitation were innovative. The entire experience was very enriching.

I no longer feel that anything is wrong with me. I am no less than anybody else. I am capable of doing so many things. I will not let HIV affect me in any negative way from here on. I have everything one needs to lead a peaceful life and I will maintain this state in the future too.

Keshav

I am Keshav. I am 23 years old. I stay in the city of Satara along with my mother. I have a diploma in medical lab technology (DMLT) and I am currently pursuing my bachelor's degree in science. I want to establish my own laboratory once I finish my final exams. My lab will be more like a collection center. Blood will be collected here and sent to a bigger laboratory for testing. I have already purchased a place to set up my lab.

I never wanted to have my own business. One needs to invest a lot and there is always a risk of loss. I would have liked to move to bigger cities like Mumbai or Pune and do research or take up a job. Even today, I can get a job in a primary health center. But for that I will need to move to some village in Satara district. My family members refuse to send me away saying that my diet and medications would get compromised if there is no one to take care of me. Staying at Satara city and commuting to the place of work in the village would have been very hectic for me.

Thus, eventually I settled on the idea of establishing my own lab. I want to start earning as soon as possible and give that money to my mother.

My father expired when I was in seventh standard. At that time, we were living with my paternal grandparents. There was no dialogue, just a huge silence in that house after my father's death. I don't know what my grandparents had in mind, but they never treated my Mummy well. She was neither financially independent nor did she have any decision making power. I think, if not for me, they would probably have thrown her out of their house after my father's death. As I grew older and started realizing this, I decided that I would start earning at the earliest and give my Mummy her rightful money.

Not only my grandparents but all the relatives from my father's side behaved in this manner. I found out about my HIV infection in a dreadful way due to my aunt's awful behavior.

At that time, I was in tenth standard. One of my friends from school, Ashwini used to stay next to my aunt. One day my aunt saw me when I visited Ashwini. After I left Ashwini's place, my aunt went to her and told her, "The boy who just visited you has HIV. Do not be friends with him!" Ashwini trusted her, as she was my own aunt.

It took Ashwini almost a month to gather the courage to come and talk to me. One day she came to me and said, "Keshav, have you ever tried to find out the reason behind your frequent illnesses? Your father had HIV. Your mother got it from him and you got HIV from your mother. You have HIV and that is the reason you keep falling sick." Ashwini was more mature than I thought. Ashwini directly came to me and told me that I have HIV. This became our little secret. Neither did she tell this to anyone else nor did she break off our friendship.

Nevertheless, after hearing this, my brain stopped working. I felt like I was frozen and couldn't move even an inch. I was in a dazed state for two days. My tenth standard board exams were just a week away. I calmed myself and thought, if I miss this opportunity, my future would be ruined.

I had to buck up. I came out of my stupor, studied hard and gave the exam.

The exams got over, vacations started and my life went back to normal. I didn't believe that I had HIV. Maybe my Mummy had it; maybe even my father had it. My Mummy possibly got it from my father. But it was impossible to believe that I had got HIV from my mother!

I knew from my tenth standard books that HIV was transmitted through sexual relations, but I did not know it could be transmitted from a mother to her child! Then how could I possibly have gotten it? And how did my parents get it

before my birth? Something was amiss. I could not figure out the truth. I thought that perhaps only my mother had HIV and I did not. My father was no more, so there was no question about his infection. And if I was infected, wouldn't my mother have told me? I stopped thinking about HIV, as I did not have it!

In retrospect, I was regularly visiting a doctor in Pune. My blood was being tested after every few months. Once or twice, I had even asked my mother about this, "Mummy, why do they test my blood after every few months?" To that she replied, "Do you remember you had pneumonia when you were young? That is why; we get your blood tested." I had accepted this answer. I hadn't understood much, but assumed that it was true, as I got what I assumed, a straight answer.

I was probably started on ART (Anti Retroviral Therapy) Medication at the beginning of tenth standard. I used to take these medicines regularly. But I never inquired about my or even my Mummy's medication. I used to have some or the other infection all the time; like cold, cough, fever. I thought that the doctor prescribed these medicines probably for preventing these ailments. I had once gone to PRAYAS when I was in twelfth standard. That time, Sanjeevani madam called me to have a word with me. She asked me, "Keshav, do you know why you always come to PRAYAS? Why are you taking those medicines?" As I did not know anything for sure, I told her that I did not know anything. She told me that I have HIV. The first thing that I asked her was, "Does my Mummy know about this? If not, then please don't tell her anything. She will be shocked."

Even after I had this conversation with Sanjeevani madam, I was behaving as if I knew nothing. I probably was in denial. But soon the side effects of the medicines I was taking started becoming visible. The shape of my face started changing, I got a lump of fat on the back of my neck, cholesterol levels in my

blood started increasing. That was the time I realized, that I could not be in denial anymore. I was also reading about HIV in more detail in my twelfth standard textbooks.

I found out that HIV could be transmitted from a mother to her child. Thus, I realized that possibly even I could have HIV. The visits to the doctor, all my medications, everything started making sense.

There were times when I still could not believe it. Not a single person close to me had ever told me anything about my infection. But then, people at PRAYAS, my friend Ashwini, information I was getting through books, the medication I was taking....were these all fake?

Slowly my irritation started increasing. I was bothered by several questions. 'Why had I become a target? Why was I supposed to take medications?' Sometimes, I got so stressed by these questions and thoughts that I used to push everything aside and clear my mind as if nothing had happened. During the day, when I was busy with my work, I never thought about HIV. But the thoughts came flooding back to me when I would lie on my bed at night. I have always projected an image of a straightforward guy, who has nothing to hide. But now I had to try hard to keep such a big secret from people. I could not eat out whenever my friends did; I had to take medicines without anybody finding out about it. If somebody did see me taking medicines how would I answer their questions?

Initially I seldom gave an outlet to my anger. But eventually the intensity and frequency of my anger grew; I started shouting at my family, started verbally abusing them. This anger turned into rage on some occasions....

I had a girlfriend, when I was in college. We were in love with each other. I could not figure out a way of telling her that I was on some medication. I soon realized that there was no future to our relationship and this infuriated me. I could not digest this sorrow...I remember raising my hand to hit my

grandmother in this fit of rage and now I feel terrible and extremely ashamed about it.

My father was a patient of hemophilia. In this disorder, the blood does not clot normally. Thus, sometimes, even a small injury can lead to heavy bleeding. Hemophilic patients need frequent blood transfusions. My father had most likely contracted HIV through one such blood transfusion, wherein the blood being transfused was contaminated.

My father probably did not know about his HIV infection before his marriage. But I am sure he knew about hemophilia. I was angry at the fact that he did not inform my mother about this before marriage and tricked her into getting married. Hemophilia being a hereditary disorder, I blamed my grandmother for passing it on to my father. I held my grandmother responsible for everything and thus she had to face my wrath. I had shouted at her, "You are responsible for all this mess. You are the filthy one here. You infected my home with your filth." I had gone berserk with my frustration.

My grandmother was actually not responsible for any of this. If anybody was to be responsible, it should have been my father. Was he responsible enough? The mystery would always remain unanswered. But I was very angry with him. As he wasn't there any more, I lashed it out on anyone who came in front of me.

Two different individuals had told me about my HIV on two different occasions. However, I still wanted to confirm it from Mummy. Once I was reading a book about HIV at home. When Mummy entered the room I was sitting in, I called her close to me. I pointed to the page where modes of HIV transmission were given and asked her, "through which of these modes were you infected?" She was baffled by the directness of the question but later very calmly; she explained to me whatever she had been able to understand.

Once I confirmed the fact from Mummy, I never ever spoke about HIV again in my house. As I gained more knowledge about HIV, I understood that perhaps my father was not at fault and Mummy definitely had done nothing wrong. And I calmed down. I made peace with the fact that this was my fate and I had to accept it as it is.

Looking back I realize that the way I found out about my infection was simply horrible. Instead of finding it out from my friend, one of my close family members should have told me about it. I would have been more comfortable with them and would have felt their support. In this case, I felt that I was all alone. Even outsiders knew about my infection but I did not have a clue about it.

Even if a family member would have disclosed this to me, I would have definitely felt agitated after coming to know about my infection. But at least my family would have known the reason for my agitation. Here, they were completely clueless about my temper as they did not know that I had found out about my HIV from someone else. The reasons which angered me were that my family members did not tell me, they cheated me, they hid such a huge thing from me. These wouldn't have remained valid reasons if my family members had told me.

Parents should be the ones to do such an important disclosure to the child. The child may get less angered if told by parents. This disclosure should not be delayed too much.

One has to abide by some restrictions if one has HIV; not to eat roadside food, only drink boiled water, and avoid ice cream or such items. A young child will find this troublesome. If that child knows the reason behind the restrictions, it would be easier for him/her to adjust to the situation more easily. One must ensure that the child does not have any other stress before

adding the stress of this disclosure, like exam etc. If explained properly, even children would be able to understand and accept the fact.

A lot of progress has been made in the field of HIV. Who knows, someday somebody may find a cure for this disease! Look at me....I am regularly taking medicines and leading a normal life.

How do the elders expect that children should find out and understand everything on their own without anybody telling anything? A child who is frequently visiting a doctor and taking medicines everyday would definitely have some questions. Adults should not wait to answer the questions till the child raises them!

It is clear to me that I have HIV and I have to live with it throughout my life. I can carry this burden because I have the support of my family and friends. I am not alone. I have constant support from my maternal grandparents and my maternal aunt-uncle. Besides, I have many friends. With so many supportive people around I have the confidence that I can spend my life happily.

I would like to have a girl as my life partner, but I would never deceive her. I would tell her about my infection. If she agrees to my condition and the repercussions it might have on her life and then agrees to be with me, I would be ready to marry her. Her decision should be well thought out. Once she agrees to marry me, after that I would not tolerate anyone saying that it was an unfair deal for her. I would not complain if I never find such a partner.

I have to ensure only one thing; my children should never say that our father deceived our mother! That it may or may not be the case is a different issue. But it should never even cross anyone's mind that there is any deception in my relationship. I feel that each one of us has to take this responsibility.

I am working on strengthening my mental capability to deal with this HIV, which is a part of my life now. The stressors, which HIV had created in my life, have almost diminished. Everything is now back to normal for me; eating,

chatting, studying, and preparing for the laboratory, going out with girl friends, everything.

I have started worshiping God since past 2-3 years. I pray to Lord Krishna. I get a lot of positive energy through this. I am sure that my God will always be there with me and see to it that I make it through all the difficult situations in my life!

Gauri

My name is Gauri. I stay in a small village near the city of Kolhapur. I am 22 years old. I stay with my mother, my younger brother, and my maternal grandfather. Can you imagine a typical Indian village? That's my village; picture perfect! A river flows through it. There is a small bridge over this river. There are houses on both its banks. Most of the people cultivate sugarcane as the river has ample water throughout the year. Although our village is small, it now has a school, a hospital, and a small theater. I enjoy watching films and plays in the theater. I have also had several dance shows in this theater.

I love to dance, but I never have had formal dance training. I choreograph my own dance numbers by watching Bollywood songs on T.V. People invite me to dance during Ganesh festival or Navratri festival. Just like dance, I love to tell stories.

I love to write and tell stories. I would have loved to hear them too! I had a friend when I was in school. Many a times, I used to go to her place for sleepovers. I still remember that after finishing dinner her mother used to tell us stories while putting us to bed. I simply used to love this entire affair. I used to long for my mother to tell me stories at bedtime.

But this never became a reality for me. My father expired when I was about 3-4 years old. My brother was just a few months old at that time. My brother and I became the responsibility of my mother, entirely. She now needed to look for some income generating activity.

An overworked, tired person- this is the image I have of my mother. I do not remember her sitting idly, going out with friends, or attending any functions with family. She used to work on someone's farm the entire day and then do house chores after coming home. She used to get so tired by the end of the

day that she used to sleep instantaneously once she lay on bed. How could I ever ask her to tell me a story!

Nevertheless, my world of stories did not end. I used to create my own stories. Today I am going to tell you a story too!

There once lived a King and a Queen - Yogeshchandra and Lata. The King was ruling well. The people in the Kingdom were happy with their King. The Kingdom had progressed well under the King's regime.

The King and Queen were deeply in love with each other. They were soon blessed with a cute little baby girl. The little princess was named Rupali. The King adored his lovely daughter.

Few days after princess Rupali's birth, Queen Lata became pregnant yet again. During this pregnancy, the royal doctor performed several tests on Queen Lata's blood. Her blood was also tested for HIV. The HIV test came positive - the Queen had HIV. Everybody was scared. Who was going to inform the Queen about this! The Queen was finally informed after the birth of her son. Initially, she did not believe what the doctor was telling her.

She summoned King Yogeshchandra. The moment the King entered her chamber, the Queen started crying. After the initial outburst, she told the King about the diagnosis. The King became numb after listening to the diagnosis. And then he himself started crying. The Queen was taken aback looking at the King himself, crying.

"I have made a mistake O' Queen. Please forgive me! I have always known that I have HIV, but I never told you about it. You have got the disease because of me. I am at fault. Please forgive me. O' please forgive me."

On the doctor's advice, both Princess Rupali and Prince Amar were tested for HIV. As the doctor was aware of the Queen's infection during her pregnancy, he had administered her medicines to prevent the infection from going to the

child. Fortunately, the medicines had worked and Prince Amar did not have the infection. But the poor princess was infected with HIV.

King Yogeshchandra could not bear this news. His health had already deteriorated because of HIV and he died!

The Queen and her two children were left all alone, on their own. After the King's death, they become very poor. Their royalty vanished. But the Queen did not lose hope. She fought back.

She worked hard to get medicines for Princess Rupali. She took good care of Rupali.

Should I tell you the truth? This story is very similar to my situation. Yes, I am infected with

HIV! The fact that I was infected by the HIV virus was disclosed to me when I turned 18 years old. My mother revealed this truth to me. I, thereafter, created this story.

I am that kind of a girl who has always lived in a dream world of stories. Recognizing this, had my mother revealed this bitter truth to me in the form of a story, it would have been easier for me to accept it.

She had not told me anything till I was 18 years of age. All along, I was on medications and I was abiding by the restrictions. I had tried to ask my mother about this on several occasions. But each time, she used to say, "I will tell you once you are mature enough, when you are 18 years old." I kept quiet and accepted her decision, as I trusted her. But it came as a huge shock to me when I came to know at the age of eighteen. I never even imagined that I was up against such a horrific disclosure.

I felt extremely dejected when I found out. I started getting irritated at all things. 'Why did I get this? What should I do now? How would I spend the rest of my life? Would other people stop talking to me, if they found out? What would they think about me?' Sometimes I used to get so stressed by these

thoughts that I used to feel like hitting the person in front of me with whatever I could lay my hands on. I used to feel like breaking, destroying things at home! I would not have reached this stage of anger if my mother had prepared me from a much younger age. I was angrier at the fact that she hid this from me for so long.

I got to know more about HIV through the workshop that PRAYAS had organized for us. How does one get this disease, how do the medicines work, how can one spend a normal life with medication, how to take care of yourself how to lead a tension-free life – these were some of the things that were discussed at the workshop. I made new friends there. Now I try to remain as happy and content as possible. I try to keep myself busy with something or the other.

Every parent is aware about the nature, the attitude, the likes and dislikes of their child. Children know what their parents don't approve of and very skillfully refrain from doing those things.

Then why do parents fail to reciprocate in a similar way? Why do they not treat the child in a way most suited to the child's temperament? Do parents ignore us assuming that we are too young to think? I would like to make one thing very clear to you - Parents: we, the children, can pretend that we have forgotten about a certain thing. But we carry the impressions of that incident throughout our lives!

Amar

I am Amar. I am 20 years old. I live in the city of Pune with my mother and elder brother. I work in a shop. I dropped out of school while I was still in eighth standard. I took up a job immediately after dropping out of school and have been working in the same place, doing the same work ever since.

I fell terribly ill when I was 10 years old. I was ill constantly, with fever and stomach ache. We visited many doctors and health facilities for almost two years. I used to feel well temporarily, but the illness used to return in a few days. On one occasion I was admitted to Ruby Hall, a multispecialty hospital in the city. The doctor at this hospital diagnosed my HIV infection.

An NGO is active in the slum community, where I live. They work on several issues present in the community, especially on issues related to children like education, health, etc. This NGO helps us out in many ways. They organize several activities for the children in the community.

The NGO also works in the area of HIV. This NGO took a lot of efforts for my HIV treatment.

Today I am able to tell you my story because of their efforts.

A lady working in that NGO told me about my HIV infection. I did not understand all the things she told me, but I definitely felt her empathy. She was the one who took me to PRAYAS. My treatment continued at PRAYAS thereafter.

That lady and PRAYAS are all that I ever had as support. I do stay with my family, but I do not have their support in any way.

My father expired when I was very young. I could never experience what a father's love or guidance was. I have my mother, but we do not get along with each other. I sometimes feel that it would be better for her if I die. She too has expressed this sentiment on more than one occasion.

My mother is tired of being alone, of the struggle for mere existence, and now she is tired of having this dreadful disease. She has not accepted her own disease and she does not want to take responsibility for my disease either.

Her reasons may be many or just one, but this means that I am all by myself, on my own. My brother treats me better than my mother, but he is tied up with his work. He has to look after the house. If somebody treats you well, that does not mean that you feel the support of that person, does it?

You must be feeling sorry for my state, don't you? But I do not feel that is so. I am not the only person in the world to be alone, all on my own. There are so many children in this world who do not have the expected support from their family. Some children have no family at all. I am just one of them.

I have accepted the fact that I am probably going to be alone all my life. I no longer feel bad about my loneliness or my mother's weird behavior. I ignore her comments, so that I don't get hurt. I work and have become self sufficient so that I do not have to beg anybody for help. I earn enough money to take care of my living as well as my treatment.

A human being requires support for living. He or she can seek this support from the family, from organizations or individuals who are willing to help. If one has the urge to survive then one finds support from some place or the other. If one gets the required support from the family itself, well and good! If not, then also it is never impossible to survive.

I have decided that I want to live. Isn't there something special in the fact that I was born as a human being? If I would have been some insect, anybody could have squashed me. But I am a boy, who has an identity of his own. If I have been born as a human being, then I have an equal right to live, like anyone of you!

Who is society to decide that I have less of a right to live just because I have HIV! Until a few years back, children having HIV did not survive at all. But that

is no longer the situation now. Now we kids are living and living happily, mind you! The day might just come when there is a cure for this disease, who knows?

One has to decide for oneself if one wants to live positively with that hope for cure or one wants to complain and cringe all the way to the grave. However, this has to be an individual's decision, not the decision of the parents or the society.

Are you giving this decision-making opportunity to your child? Or are you looking after him thinking that he is going to die sooner than later? Please introspect if you are a parent.

A few of us coming to PRAYAS for treatment have formed a group. We are all children/adolescents living with HIV. To quote one of my friends from PRAYAS, "HIV is one of the many different colors in our life. But this is not the 'only' color in our life. There are many more colors too!" I was able to truly understand my state only because of his statement. My perspective of looking at my life changed.

I do not feel that my situation would have been very different in the absence of HIV – my father could have still died when I was young, I would have required to work and drop out of school, I still could have got this weird mother, and my life would have continued to remain gloomy and painful. Perhaps I would have lacked the perspective of looking at life positively, which I gained due to HIV. I would not have felt that I am different, special. I have realized my right to live, only when somebody is trying to steal it, when somebody is telling me to die. I have realized that I have to exercise my right; I am not going to get it on a platter.

Children survive with or without parents. We are survivors. The impulse to live is heightened if one is aware of all the colors one has in his/her life. I am

therefore looking at all the colors in my life; I am trying to understand what each color means. I am living....

Aboli

My name is Aboli. I am 24 years old. I got married this year and now I stay with my in-laws, in Saswad. My natal family lives in Pune. I have three sisters. We do not have a brother. I am the eldest one. One of my younger sisters got married last year; the other two are still studying. These two sisters and my mother live in Pune.

We have always lived in Pune. My father had a small business in Pune. In the beginning, it was going well. Then my father started drinking heavily. He lost his house, and his business to fulfill his addiction. We had to leave the city and go to my father's village. We stayed there for 2-3 years. My paternal grandmother gave my father some money to restart the business. We once again returned to Pune. Again the initial days were good. My father provided for the family financially as well. But yet again he got influenced by bad company and his drinking resumed. Every 1-2 months my father fought with my mother and left the house to go and stay with his parents in the village. This went on for many years. But once he just left and never came back. We tried to search for him, but were never able to find him. We don't even know if he is alive or dead. But he is no more for us, with us.

I had completed my twelfth standard by the time my father had left us. Even after he left, my mother encouraged us to study further. I am still studying; pursuing my bachelor's degree in commerce.

It was not easy for my uneducated mother to fend for four girls and to take care of their education. I started earning once I realized this. Since then I have been working and pursuing my education simultaneously. My other sisters have also been working on and off.

Listening to my story till now, you mustn't have felt anything amiss, right? It is a typical story of a girl from a poor family, that's it. You must be thinking now

about how exactly I found out about my HIV infection, correct? The answer to this question is a bit different, rather unexpected. I came to know about my HIV infection when I was 22 years old. And the rest of the people, my mother, the doctor, all found out at the same time.

I never fell seriously ill for 21 years of my life. I had minor ailments. But that was about it, nothing serious. But I started falling ill frequently in this 21st year of my life. I was constantly ill with cold, cough, fever, stomach infections and so on. By the time one infection got better, the next one started. I consulted many doctors, went to several medical facilities, but there was no improvement. Once, my health deteriorated considerably and I was admitted to a big hospital in the city. Several tests were performed, HIV was one of them. The doctor was astonished to see the report. Looking at my age, my mother's healthy state, and lack of any prior reports, the doctor assumed that I had got HIV due to my behavior.

He called me when I started feeling better. Without even explaining the purpose of this meeting, he started bombarding me with questions. "Have you had sexual relations with anybody, did someone try to rape you? Do not be afraid. Just tell us his name. We must find him as he also might have this illness."

I could understand what he was asking me but I could not comprehend why! As he could not get the expected answer from me, he at last told me that I had HIV. I was stunned! The information given in school about HIV flooded back to me. I remembered the lecturer telling us that this illness was spread through sexual relations. I had not experienced anything like that. Then how did I get this disease!

He called for my mother and told her about my HIV infection too. She did not doubt my behavior, she knew me well enough. But the questions did not leave me. How did this happen when I had not done anything wrong? I was

constantly crying. I was not talking to anyone. I was referred to PRAYAS from this hospital. I was asked similar questions in PRAYAS too. I was getting too stressed by these questions. As the source of the infection could not be traced through my answers, they called my mother for testing. Her HIV test came positive and at last, I found answers to my questions. My mother had HIV and I had got it from her at birth.

Initially, my mother did not believe that she too had HIV. She used to say, “I do not understand how I got this disease! How did I survive for 20-22 years if I had this disease? All these years, I was never sick; I never took an injection for anything. I do not believe that I have this illness.”

She used to get irritated and angry with me. We used to fight a lot as she was not ready to accept and understand the reality. Not one but both of us had HIV; whether she accepted it or not!

However, we still wondered about my mother’s wellbeing. The doctor at PRAYAS explained it to us, “Though very rare, this may happen in some cases. The growth of HIV in some individuals is very slow and that is how you have not had major illnesses.” I calmed down as my questions were answered. I regained my confidence when I saw that everyone believed that I had not done anything wrong.

I decided that I have to conquer this HIV. I could not let it win. The fact that I was fine for all these years meant that there was something more written in my destiny. I would not let my life go waste.

I told my sisters about the HIV infection that both my mother and I were suffering from. They all were tested for HIV. Fortunately, none of them was infected. They accepted us well and never treated us poorly or differently.

Other relatives of course did not know anything about this. As they felt that I had become of marriageable age, they started suggesting prospective grooms. I gave different reasons and refused to marry. Once, one of the

grooms suggested was so good, that any reason for refusal would have raised suspicion. So I suggested my younger sister's name for that groom. Both of them liked each other and she was ready to get married. Thus, my younger sister got married before me.

Relatives still talked about this affair. "How can they marry off the younger one, when the elder sister still remains unmarried?" Some of them even taunted my mother saying, "You did not marry your elder daughter because she is the breadwinner of your family!" People will always talk. They would have still commented had my mother married me off without informing the groom about my HIV. "She knew, yet she married her daughter off. Is this behavior appropriate?" Thus, one has to decide for oneself how much importance should one give to people's whispers.

I was studying. I wanted to complete my education. The groom's family accepted this reason. My family knew the true situation. We firmly stood by each other and went through the ceremony without a hitch.

As the days went by, I also learnt from PRAYAS, that one can get married in spite of having HIV. One can get married to another HIV infected individual or one can get married to an uninfected partner with his/her full knowledge and consent about the infected partner's status.

After getting to know this, I started thinking about my marriage and started taking efforts to fulfill this objective.

Arranged marriages in our society are not uncommon. Now-a-days large meetings of prospective brides and grooms are also arranged. One day my mother's employer read an advertisement about such a match-making meet especially for HIV infected individuals. She knew about my infection and thus told my mother to take me to this meet along with two of my photographs to register my name. We went for this meet and registered my name accordingly.

After going to the meet, within two hours a boy liked me as a probable match. His family took us to show their house immediately. Later they also came to see our house and where we lived. But they conveyed their refusal after two days. We later found out from the coordinator of the meeting that the guy was addicted to drinking.

The second time, the coordinator called us to meet a prospective groom from Latur. That marriage too was finalized. However, his family was not aware of his HIV status, so we did not get married immediately. We used to talk on phone. Sometimes he came to see me in Pune. After a month, he started saying, "Let us not get married as of now. Let us just stay this way. We shall talk on phone. I shall visit you. But till the time my family does not approve of you officially, I cannot marry you." I thought this behavior was weird and I broke off the marriage.

I was now tense as this had happened twice. But I felt fortunate that I found out about the odd things before marriage. If I had found out after marriage, it would have been difficult for me to spend the entire life with a drunkard or a weird individual.

I continued with my efforts. I continued facing and fighting all the difficult situations. I had decided that come what may, I would not turn away from any situation. In retrospect, fighting out any situation was not an inherent personality trait. But I become tough because of this illness.

The third time, I met this individual from Saswad, whom I eventually married. His family insisted on immediate marriage after meeting me. I had liked the man, but I had become cautious due to my previous experiences. Both of us agreed on the thought that we needed more time and we were able to convince his family.

The time we got, we spent well. We used to talk on phone. He used to visit me too. I then took him to Dr. Kulkarni and he took me to his doctor. Both the

doctors saw our medical reports and gave their approval on medical grounds. They did not see any problem in this match from the point of view of HIV. We later got married.

While looking at prospective grooms, I had considered their education, payment at work, standard of living and so on. We had calculated how much money was left in hand after spending on our medicines and treatment. That was a major point for considering the match.

The point to convey here is that, we children are much more competent than our parents believe. So many children have shown this time and again – if the household needs money, they start earning; they look after their younger siblings. If both the parents have to work, they do the house chores. We can take all such responsibilities. You parents trust us with house hold or work-related responsibilities. Then why don't you trust us when it comes to disclosing about HIV?

Do you feel that we won't be able to take it, to bear it? So many children bear a drunkard father, a mother's hardships, and responsibility of the family in young age etc. Then why won't we be able bear the burden of HIV?

Probably your child has not faced such hardships. But that does not mean that he/she is not bothered by any questions. And some day or the other they will find out about their HIV. So why not tell them at an appropriate time and from an appropriate individual?

There wasn't any issue of non disclosure in my case. However, the questions did not reduce when I found out. But I did not lose hope. I fought it out.

I am not claiming that we are right about everything. But we young people can definitely see what is advantageous for us. We do require the support, guidance and trust of elders. I just want to tell you that please start trusting us, youngsters more.