

# TB: THE TICKING TIME BOMB

STORIES OF LOSS, STRUGGLE AND HOPE



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# INTRODUCTION

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Dear Reader,

In the month of October, 2014, *Satyamev Jayate* devoted an episode to the grave issue of Tuberculosis in India. The episode sought to underscore the fact that tuberculosis in our country is a ticking time bomb ready to explode. The episode and the live show, *Mumkin Hai*, that followed, drew an enormous response from all over the country. While some took to Twitter, Facebook and our website, others reached out via email, letters and phone calls.

During the field research for this episode, my team members and I personally came face to face with the deadly and heartbreaking reality of tuberculosis across rural and urban India. We felt the need to lend a hand in fighting this battle at multiple levels in a multitude of ways. The episode itself was one such way. And when the feedback to the episode poured in, we found that the stories that people generously shared were moving, enlightening and important. So we thought of compiling these diverse messages into a booklet and sharing them with you. We do so in the belief that these stories of pain and of hope could be of some use to someone, somewhere.

On the afternoon of June 8, 2015, while we were in the throes of editing this booklet, my phone buzzed. It was a message in Marathi that read: “*Akshata SSC pass zhali. Tila 61 takkey marka milalaa.*” (Akshata has passed her SSC exam and obtained 61% marks.) I was so overwhelmed by this piece of news that it took me a moment to register the second sentence of the message: “*Don varshaa nantar tichaa TB cha report pahilyandaa normal nighaalaa aahey.*”

Akshata is the 14-year-old daughter of Vishwanath, a Mumbai-based cobbler, who had taken loans and spent thousands on her Multi Drug Resistant TB treatment, but to no avail. He contacted our team after watching the episode. We were fortunately able to connect Akshata to Médecins Sans Frontières and with their help, she not only received medical treatment and checkups for free, but also ration and emotional support—services that she didn’t imagine were available for TB patients.

Hundreds of helping hands are reaching out to TB patients in our country today. Doctors, nurses, DOTS providers, community organisations—with dedication, empathy and courage, they heal hundreds of Akshatas every day. For the thousands of tuberculosis patients in our country these healers are a ray of hope in an otherwise bleak landscape. This booklet is humbly dedicated to our healers and their valiant patients.

Svati Chakravarty

Co-Director and Head of Field Research

Satyamev Jayate

June 2015

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## STORIES OF LOSS

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My 24-year-old sister Samidha, a doctor herself, passed away just 6 months after getting TB. We did everything we could but we still couldn't save her. My parents came to the hospital twice—the first time to get her college admission done and then, to take her body home.

- **Dr Shekhar Khandare**

In our episode on Tuberculosis that was telecast on October 24, 2014, Dr Shekhar Khandare shared the story of losing his sister Samidha to the disease. Many other families have also lost their dear ones to TB—some at a very young age, some within months of getting the disease and some after a prolonged period of pain and illness. Find here some of these stories shared with us by our viewers.

“

When I was 13, my 11-year-old sister Rupal got TB. We thought it was normal fever and first put her on antibiotics. She kept coughing a lot and then the doctors gave her cough medicine. After two months we realised that she has TB but just a month or so after putting her on the TB medication, she passed away. It was too late. She was one of the most charming and beautiful members of our family but TB affected her physically and mentally. We were so happy when we saw your show because it gave us hope that others who see this will not wait for long before getting checked for TB.

”

- Saloni Singh

“

My uncle passed away of TB in May 2014. Government doctors told him to buy drugs from private doctors and vice versa. He was then told that there were no medicines even at the district level. His daughter-in-law went to the hospital 6 times to get medicines but she couldn't get them even a single time. His sickness increased. He stopped eating and no doctors or medical staff helped us. Finally, he fell very ill and passed away.

”

- Raman Asharam  
Uttar Pradesh

“

I wanted to share my experience on this deadly disease due to which I lost my three-year-old daughter who was suffering from TB-meningitis during the year 1982–83. Initially she got fever and when antibiotics didn't work, we took her to a child specialist. He prescribed another set of medicines that didn't work.

We sought a second referral from a more eminent child specialist who said that it is nothing to worry about. Basically, both the child specialists didn't have the time for diagnosis of such a serious disease. The delay in diagnosis and wrong medications became fatal. Finally, we correctly diagnosed through another doctor whom we took her to because she had unbearable back pain and was crying a lot. It was too late though. She passed away in the next 2 months. We need to have better treatment facilities for children with TB.

”

- K. K. Sinha  
Patna, Bihar

“

I am a 20-year-old and I live with my nana and nani. My younger brother was affected by TB in Roorkee in 2011. His treatment started in Delhi and after six months he became normal. After 2 to 3 months, my 17-year-old sister was affected very badly with TB due to which she lost weight too.

After 6 to 7 months, she became okay. But I didn't know that my mother, 38 at the time, was not taking proper food and my father was not caring for her the same way. I started my mom's treatment in Mehrauli and she became better after 3 months. Someone then asked her why she was still taking the medicines and so she stopped.

On December 31, my sister called me and we had to admit our mother in the hospital. On January 4, 2014, I lost my mom. Till now, I have no support from my dad and his family. At the time of my mom's death, one of my younger sisters was diagnosed with TB and I also suffered from vomiting of blood and shortness of breath. The last stage of treatment is going on for my sister and we both are fine now.

”

- Azad  
Delhi

“

My husband used to work in the brick kilns. He was coughing a lot and blood used to come from his mouth when he coughed. He started taking medicine but his boss said that his coughing is because of a reaction caused by the medicines. He stopped the medicine and started coughing again. Then his treatment was started again for a year. He fell ill again and we took him to Allahabad.

After five months of treatment there, a government doctor told him to take treatment from a private doctor as he was too serious and could not be saved. He said he would slap my husband if he didn't get out. The private treatment would cost Rs 50,000. We didn't have the money and because of medical negligence and lack of care, my husband passed away.

”

- Boniya  
Fatehpur, Uttar Pradesh

“

I would like to share my experience on the TB disease. My mother suffered with the very same disease i.e. TB in the brain, which had travelled through her spine due to which she was bed-ridden.

My mom was not responsive to the first level of basic drugs that is AKT-4 and Rifampicin actually had a negative effect on her due to which she faced a Kidney Failure and the medicines didn't have the needed effect on her. But I was never educated on the Second Line of Drugs and in fact, the doctors were never ready to support properly.

She was not even treated properly in the hospital and was sent home saying that she was indeed improving. But in two days she had water logging in her body and was admitted to the hospital after which she never came home. She was put on Ventilator and finally gave in in less than 18 hours.

”

- Rajni

“

I have experienced one real life struggle by a husband (a good friend of mine) whose wife was suffering from this disease before his marriage but his in-laws did not admit this thing at the time of marriage which led to the third stage of TB and he could not save his wife despite several diligent efforts and even his child could not survive before birth.

”

- Namit

“

Mera langotiya yaar, jiske saath main apne pehle 10 saal tak tha, woh aaj duniya mein nahin hai. 14 years ki age mein uski death ho gayi. Usko TB ki bimari thi aur main uske liye kuch nahin kar saka, mujhe uska dukh hai. Mere village mein ab tak bahut se log TB ki bimari se gujar gaye hai. Ek-do family mein koi mard hi nahin bache hai!

”

- Vinod

“

When I was only 8 years old, my father died because of the TB disease. But my mother educated me.

”

- Kirit  
Saoner, Maharashtra

“

One of my uncles suffered from TB and it is only in the last stage that we got to know that he was suffering from TB and there was no chance of survival. He was hardly 37 years old that time and had a 3-year-old daughter.

”

- Aswini

“

My father had TB in 1949. There weren't much treatment facilities in India then. My mother spent all her savings on his treatment but still my father passed away. The episode reminded me how we survived - it wasn't easy.

”

- Bhushan

“ I lost my mom in January 2014. She suffered very badly. I started her TB medicines before her death but she left midway of the treatment. ”

- Arish

“ Last year, I lost my brother to TB. He used to work in a photo lab in Delhi. Many years ago, he suddenly started feeling unwell and since the pain was unbearable he went to our village to get treatment. That's when he learnt that he had TB and was given medications. Once he felt better, he resumed work.

Seven years later, he had a relapse of TB - it was MDR TB. After 2 to 3 months of taking medication he felt better and thought that he was okay so he stopped the medication even though the doctor said that he had to continue the medication for 6 months.

My brother got so many side effects because of the medicines that he felt he was going to go mad. He used to tell me that instead of going mad because of the medicines he would rather not have them and die. He would sweat the whole night and couldn't get out of bed on some mornings.

The DOTS centre staff called us 2-3 times to check why he has stopped coming to take the medicines. We told them the reasons. There was no call or visit from them after that.

”

- Kasi

“

I have survived TB in 2009. I came to know I have TB in the 6th month of my pregnancy. My daughter was born in the 7th month. My treatment went on for 3 years, from 2009 to 2012. My daughter Sarika got TB meningitis after 6 months of birth.

She became paralysed on her left side of the body, could not see from her left eye, could not walk, talk. She suffered for 2.5 years and underwent 5 surgeries. We then got her treated at AIIMS Hospital for 1 year and 8 months but in 2012 she passed away. She will always be my inspiration. I love her and miss her a lot.

”

- Sunita  
Mumbai, Maharashtra

“

I lost my father due to TB. After 5 years of my father's death I came to know today after watching the episode why following regular treatment and visits to doctors didn't help in curing him.

”

- Chhaya

“

My dad was a victim of MDR TB. The side effects of the medicines were too much. My dad started being mental. The doctors were not friendly either. They treated us as untouchables. Unfortunately my dad passed away few months back due to the overdose of antibiotics.

”

- Archana

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## STORIES OF SUFFERING AND PAIN

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I cannot even begin to describe the pain I went through. I had to take 400 injections. I could not digest any food. I couldn't even see my baby daughter or hold her in my arms when she was born.

- **Dharmesh**

In our episode, Dharmesh, a bank employee, recounted his struggle with TB. From extreme side effects to having to take numerous injections, the emotional and physical pain that many TB patients undergo is difficult to explain, with everyday survival itself becoming a challenge.

“

I was suffering from MDR TB; I completed my course successfully in August 2014 and today I'm cured. It was in the month of January 2012 that I experienced pain in lifting my arm and I found some swelling under my armpit. After conducting sonography, the doctor said it is tuberculosis and I undertook first-line medication for 6 months.

In between, I had my TY board exams and took 1–2 hrs to reach the distance of 20–30 mins of my exam centre because of heavy Mumbai traffic during peak hours. I used to daily vomit 2–3 times on my way to the exams. I almost fainted during the start of my first exam paper and started writing my paper 30 minutes later.

The college staff supported me a lot and gave me instant energy drink and allowed me to sit with pillows and food for the remaining papers. Doctors advised me not to give the exams but I did not want to waste a year. After almost 6 months of medication there was no change, no improvement in my health. Local doctors failed to notice that I was not getting cured. Suddenly one fine day, white fluid burst out from my armpit and I underwent second surgery.

Yet the doctor felt I was normal and I should continue taking my medicine and come to visit him again in some months. But my family was not willing to accept this decision of doctor. So immediately the next day we took appointment of Dr Zarir Udwadia of Hinduja Hospital.

I cried for weeks because I was very scared of injections and I had to drop my final CA classes which I attended only for a month and had my exams the next year. I took a break from studies. I took 140 injections and approximately 25 medicines in a day which after 3–4 months reduced to 10–12. The side effects were so bad that I was once diagnosed with drug- induced jaundice.

Each day was spent with a new problem fighting with side effects. The worst part of this treatment is vomit which in the initial months was about 8–10 times a day and later on, to once or twice a day till I took my last medicine. Other side effects I experienced were joint pain especially unbearable leg and back pain throughout the course, oral thrush and rashes on the skin, and change in skin colour, which was the worst experience.

I somehow completed this treatment and today after completion of 9 months of my medicine course still I am taking vitamins tablets and my skin colour has not yet come back to normal. I'm hoping to resume my studies and live a normal life.

I would like to thank Dr Zarir Udwadia and my family and some friends. Without them, I wouldn't have been here.

”

- Riya

“

I had intestinal TB which had spread throughout the body and had affected my lungs, sparing only my brain and bones. During this lowest point in my life it was only my parents and close family who stood by me. I was pregnant and didn't get good care post delivery in terms of nourishment and rest. I had very low resistance and then to top it all, had a miscarriage which further rendered me weak and susceptible to this illness.

The disease got ignored for 8 months as I was in Nigeria with my husband. There they kept trying to find out what was wrong but to no avail. When they couldn't diagnose my illness I was sent back to India. I came back with a weight of 35 kg and haemoglobin of 5.

What disappointed me was the discrimination from my in-laws. They stayed away from me and visited me only once and that too with precautions. I was told very strictly by my mother-in-law that I was not to disclose my illness to anyone. I stayed with my parents for almost a year and with them looking after both me and my daughter. Though it's been 19 years but that still hurts.

I would just like to add that this disease doesn't discriminate between rich and poor. It can strike anyone with a low resistance as it is airborne. There is nothing to be ashamed about so talk about it and let people know how to cope. It is very traumatising to find out that you have TB, so family support is essential.

”

- Monika Sharma

“

I got gall bladder stones and was being operated for them. That's when the surgeon realised that the lymph nodes don't look normal. He explored a little more and after biopsy, it was diagnosed that I have TB of lymph nodes.

Literature says that extra-pulmonary TB is even more fatal and difficult to cure. My treatment was without Rifampicin since I was very allergic to it. I got skin rashes, high fever and vomited every time I took it. I now dread a relapse, even a mild fever scares the hell out of me.

”

- Sheela  
Delhi

“

I was 13 when I was diagnosed with TB in my lungs. Medicines were started immediately, but it was after taking the CAT I and CAT II medication that doctors understood that I had MDR TB in lungs. During the course of CAT I and CAT II, I missed my schooling, mainly because the medicines were provided alternate days at a time (9 am - 2 pm) at which I was supposed to be at school. So I had no option other than missing my school.

CAT I treatment went on for 6 months and then the CAT II medication was for 9 months. After both these medications, TB relapsed again. This time I was put into the MDR drug medication which was way more toxic than the earlier ones and also costly.

This medication went on for 2 long years, and these were the most depressing years of my life, mainly because of the stigma I had to face and also because I couldn't attend my school and also there was a chance that I would be not able to write my board exams. It's been 10 years now, from the time I started treatment for TB, but the amount of medicines I ate for so long has affected all my body parts.

I have put on so much weight which I am not able to reduce since I am weak. My bones are so weak and even in this young age I have got the problem of disc issues in spine which normally people have in older age. I can't breathe easily without using asthma medicines.

I really wish our country would follow the international standards of healthcare soon rather than making the patient go through a hell of tortures. Hoping for TB free India!

”

- Ann

“

I am a TB patient and I am taking my medicine through DOTS. I was diagnosed with TB in May 2014. I don't know where I made a mistake because in the 5th month of treatment, I had severe pain in my lungs in spite of me being an extra-pulmonary TB patient. I am really upset with things around me because now in the 6th month, doctors are asking me to get an operation done on my lungs.

- Navin

”

“

I used to get frequent bouts of fever. I went to many doctors but it did not help. Finally, one doctor suggested that I get an X-ray done. The X-ray showed TB. After two years of treatment, I was told I have MDR TB. I was not counselled about this at all and though I was told I would be fine in three months, I was depressed, listless and would not talk to anyone.

The drugs gave me various reactions. I was breathless. My mother thought I was acting this way to avoid housework. But I had difficulty in walking and injections made me feel giddy and forgetful. The neighbours stopped talking to me and I had to tie a cloth around my face while stepping out.

I even visited babas as some doctors said it could be due to some paranormal influence. I blindly believed them without having knowledge about my illness. My marriage was fixed but my parents said I could not marry before finishing my treatment. Sometimes I felt like committing suicide as well. Finally I was introduced to an NGO that helped me learn more about the disease.

”

- Kavita Yadav

“

I am a survivor of TB. I contracted the infection in a hospital after a surgery about 20 years ago. It was extra-pulmonary in origin. The doctors could not identify where the infection was located in my body. I underwent many tests, spent a lot of money and a lot of time in the hospital, but there was no use. Finally, the doctor put me on Rifampicin for 9 months and I recovered from the symptoms. But I am not sure when the symptoms will resurface. I am living in that fear for the past 20 years. Another problem that has come up is that I have developed vertigo problem and people tell me it is because of the TB treatment.

”

- Bala

“

I was a diamond worker and then worked as a security guard. I have TB since two years. I took the treatment for nine months on alternate days. I continued to go to work while the treatment was on. My wife too was ill, I have two kids, and our economic condition was bad. I had become weak. Once blood came in my cough. I was admitted to a hospital at least four to five times.

I have been unemployed because I don't have any energy to work. I have spent more than 1 lakh rupees for my treatment. I find it difficult to pay for my rent. My salary was Rs 5,000 per month and I had to sell my house to pay back the loans I had taken for my treatment. I had even felt like I had become a burden and wished for death. But my wife and daughters stood by me and I feel better after seeking help from an NGO.

”

- Sangamesh Patel

“

Presently I am suffering with high resistant TB & since last 2 months I am at home and the treatment is costing me more than Rs 10,000 per month. I am a 28-year-old and an earning member of my family but since the last 2 months I am going on without pay. I know how painful and how costly it is with long treatment. So I pray to God that TB does not happen to anyone.

”

- Lavin

“

I want to share my brother's serious problem with you. He is 35 years old, suffering with MDR TB. Treatment is going on but he is alone and depressed because his father never supports him. He is a lyricist, he writes songs and stories. My father is upset, because he doesn't like this work. He only wants my brother to study hard and do as he says. So, he never helps him in any condition, no moral support and no financial help. My brother is really struggling and is fighting with his disease alone. We two sisters are with him but we can't do anything.

”

- Sudeshna

“

My maternal uncle, my late beloved mother's elder brother and sister suffered from Tuberculosis. My youngest brother is getting treatment for the same. Out of 7 my 4 family members have suffered from this disease. I request you to ask government to take immediate action on this and I am ready to support from my end.

”

- Manu

“

My elder brother is suffering from TB. He is so depressed and he cries every day.

”

- Anirudh

“

I want to say that 8 years ago I had TB and it was very painful and the worst time for me. I was so helpless because no one understood this.

”

- Zarina

“

I loved the TB episode so much that I saw it again with my husband who's suffering from TB. Only I wish I could see the episode with my in-laws who feel I am the unlucky person in my husband's life because of which he is suffering from TB. As correctly portrayed and said in the show, everyone is hit by the virus but it's when our immunity level is down, such diseases catch hold of us.

In 10 months of marriage, I have seen the worst, as a TB infected patient is vulnerable and susceptible to any virals in the atmosphere. And one that effected my husband was dengue along with TB, which was definitely not in my control nor in the doctor's control.

”

- Jayshree Nair

“

I fought and won the war against TB twice. I can say family support along with proper treatment is vital to survive. First time when I had it, I suffered physically but it had little or no effect on my mind because I was young and I had no one to worry about if something terrible had happened to me.

But the second time was a different story. I have 2 children and it injured me mentally more than anything else. I am constantly fearful that I might have it again and pass it on to my children. The scars of TB exist not only on my lungs but also on my mind and soul.

”

- Tanvi

“

I'm suffering from spine TB. Spine TB does not even allow you to die. It will make your half body die and remaining will live with no cause. As you said, time bomb is ticking - never know how much life it might take with it.

”

- Ajith

“

I am a doctor from Nepal and one of my friends who is also a doctor fought hard against MDR TB. I could feel his pain and depression while under treatment periods (first category 1 medicines, then category 2 medicines and then only MDR injections for 12 months!). We health professionals are at high risk of getting TB transmitted.

”

- Rupesh Gami

“

I am also a TB patient since 2008 and my age is 26. I am not able to fight with the disease because no doctor is able to treat me properly. I have changed around 4 to 5 doctors. And I have suffered a lot in the last 7 years. I have taken 250 injections along with all my medications and a healthy diet. Even then, I am unable to cure this disease.

”

- Hemang

“

My wife went through a very different kind of Tuberculosis which was initially found negative through several tests. However, endoscopy revealed multiple lymph nodes across pancreas and chest. It was a very painful experience to have the disease and to have a two-year-old baby that needed feeding. It took us 8–9 months to fight the disease!

”

- Amjad

“

I want to share something with you. Now I am 46. I was suffering too much mental stress after my marriage when I was 21. At that time I got TB. Doctor gave two medicines. At that time cost of one was Rs 4.50. Doctor told me I have to take it daily for 9 months. It was very difficult for me to arrange Rs 4.50 for one tablet. Now I have overcome that situation by God's grace, but thinking about the past made me too depressed.

”

- Anahita

“

Today after watching the episode on Tuberculosis, there is one story that I want to share with your team. My partner was diagnosed with TB a year back. Before TB was diagnosed, his family was not ready for intercaste marriage and had superstitious beliefs like manglik dosh and all. After TB was diagnosed, his family agreed for intercaste marriage thinking that no one would marry their son. I accepted his disease because I know anyone can have this disease. I stood by him and gave him all support that he needed.

I am seasonal allergic. I have pollen allergy usually in the month of March or November. My disease was told in advance to his mother. She didn't say anything initially because her son had TB. Now after 1 year she refused for marriage saying that her son can get a better girl physically. Reason being her son is now fit and fine. She thinks seasonal allergy is communicable which is not true. On one part Mangalyaan has reached Mars but the other part of India is still stuck in Manglik dosh, apshagun, kundli and all.

”

- Ritika

“

As someone who has spent two years recovering from TB, I promise you it's not a disease you'd wish on your worst enemy.

”

- Sonal

“

One of my uncles was also suffering from the same problem but he fully neglected it. At last his wife decided to meet a doctor and after the check-up they came to know that he was at the last stage of TB. It became very serious and difficult. So I request all to never neglect these kinds of problems.

”

- Akshata

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## AN INSIDE VIEW OF THE HEALTH SYSTEM

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The DOTS programme itself was creating MDR TB by not supplying the medicines effectively.

- **Dr Muhammed Shaffi**



I was told at the DOTS centre, “These medicines are very expensive. How much are you willing to pay us for them?”

- **Mangal**

As explained by patients and experts in our episode, a lot has been done to mitigate TB in India but a lot more still needs to be done. Read these stories to learn about patients’ experiences at hospitals and health centres across the country.

“

Many years back when I was hospitalised in a private hospital at Lormi tehsil in Chhattisgarh, I observed that one old patient had come there for treatment of severe cough. But the doctor was so cool and just gave him one injection and sent him back to his home in a village nearby without any diagnosis or tests.

Out of curiosity I asked the old man about his health and was shocked to hear that he was suffering from severe cough since last 3 years, and he used to visit the same doctor since last 3 years intermittently and take the same injections just for immediate relief.

”

- Ravish Das  
Chhattisgarh

“

I have been working under the government's Revised National Tuberculosis Control Programme (RNTCP) for the last eleven years. As we know, we cannot win any war without soldiers. But no one is taking care of the RNTCP workers who are fighting as soldiers against the TB disease.

Many of them have died due to TB infection while trying to help others. There is no mediclaim, accidental claim, no risk allowance. The field staff is on a contract basis and getting a very small salary. If the government will regularise them, it will strengthen the programme and be a big moral support for them. Please convey this message to the government.

”

- Amit

“ People are afraid of talking about TB. I have faced this problem in my own house. We have a joint family of 12 people. When my younger brother got married, we were not told that his wife got TB before she got married. It is when she got pregnant that we got to know about her medical condition and it is much worse than before.

She had MDR TB during her pregnancy. The hospitals and DOTS centres we visited said that they don't have facilities for pregnant patients - either go to gynaecology department or to a TB centre.

Finally after nine months of hell, she gave birth to a baby girl in a government hospital. The newborn baby is also taking the TB meds for one year so that she doesn't get the infection from her mother. Kindly tell the government to take steps in the right direction.

”

- Monali

“

I was a Tuberculosis patient. I recovered from it after 2 years. I want to share an experience. I was coughing for more than 6 months. I showed it to several doctors in Kolkata. No one said that I can have TB. A medicine shopkeeper said that he observed that I have been coughing for a long time and asked me to please go ahead and get a TB test done. We did not believe that.

We went to Kolkata's best MD in a very well-known hospital. Unfortunately, he gave me all kinds of antibiotics for cough relief but my illness still persisted. I was going weaker day by day. I started vomiting blood and a small doctor in my locality could understand that I was suffering from TB and my lungs were fully spoiled.

- Joanita

”

“

I wanted to share a shocking story of my mother with you. My mother got infected by MDR TB two months back. She was hospitalised in a private hospital and had diabetes as well. We immediately contacted the nearest municipal DOTS centre for the medicine and other care and they referred us to a popular government-run TB hospital.

Her situation was becoming bad day by day. She then got an attack due to low sugar level and we immediately took her to the nearest municipal hospital but they refused to take her in because she had MDR TB. Then we admitted her in the government-run TB Hospital.

After 17 days, they discharged her and asked us to take her home because they didn't have a diabetes expert with them. After a few days she got paralysis attack and we took her immediately to a municipal hospital for treatment but again they refused to take her because she had MDR TB.

No private or government hospital was taking her due to MDR TB. We were just hopeless and we couldn't afford a big private hospital too. Somehow we managed to admit her in the nearest orthopaedic hospital and the treatment was started. Even now my mom's situation is very bad but we are trying our best. Because of ignorance of doctors, my mom is facing a critical situation and pain which could have been avoided.

I strongly suggest that hospitals provide all medicines at one place - for paralysis, kidney and dialysis. I hope and pray that what we have gone through should not happen with anyone else.

”

- Sumant

“

I myself suffered from tuberculosis, second stage, had blood vomiting for 3 days continuously with clots of lung - damaged 50%! This was due to the doctor's mistake who didn't take my X-ray even after asking them, said I look perfect and what can happen to me! But the case became horrible after 3 months and I was shifted to the ICU in a critical condition. Well, I'm cured after 9 months of treatment. But such a case shouldn't happen again.

”

- Bhavika

“

My mother was detected with intestinal TB in February 2014. The doctors suggested the tablet course and all went fine till October 5, 2014. Suddenly she got stomach cramps and had to get an operation two days later since doctors said that there was a little cut in her colon.

During the operation they found a TB-infected knot in her intestine. They kept us waiting in the casualty ward for 2 days and then finally asked us to leave as there was no bed available. We moved to another hospital then. She is currently doing better and her medication is still on. But I hope she doesn't get affected again.

”  
- Divya  
Mumbai, Maharashtra

“

I am a doctor and live in the UK. Almost every member of our family including me has had TB. It is not a poor man's disease - we all breathe the same air. Living in glass houses gives a false sense of security. Why are we not proactive in contact tracing? We need to consider our employees and house help too when diagnosed with it. It is a fight we CAN win with concerted effort!

” - Nikki

“

Govt. hospitals in villages do not have a doctor on duty. My sister lives in Malur district in Karnataka state. She contracted TB a year back. She was under medication and she is cured now. But from her I came to know about the serious issues around the availability of medicines and other facilities in rural areas.

”  
- Moin

“

My wife was diagnosed with TB when we were moving to Australia. However, the Indian medical system cleared her after 6 weeks of regular tests. She was allowed to travel. As soon as she landed, the Australian medical association took over and did 3 tests in which the result was positive. It was embarrassing how the top Indian medical institutes had cleared us.

”

- Sunil

“

I am a doctor and I suffered from a rare variant of TB called endobronchial tuberculosis. I suffered when I was doing my post graduation. The place where I did my PG had highest incidence of HIV and some of the TB patients used to take second or third dose of DOTS. Many of them were defaulters also.

Patients did not have enough awareness and there was poor compliance just because they didn't feel like taking drugs. There was no facility for doing sensitivity tests in government hospitals. It costs around Rs. 5000–6000 in private labs. So I support your thought of fighting TB as a national emergency.

”

- Aneira

“

My wife Savita, age 53, is suffering from Meningitis TB since January 2012 and the treatment is continuing. It was very difficult to diagnose this. She had almost gone to the danger zone. Since 34 months, she is taking the highest dose of TB medication.

”

- Manish  
Udaipur, Rajasthan

“

It was the year 1952. My grandmother contracted bone TB and just imagine those days with very little medical assistance. She was admitted in a sanatorium in Himachal Pradesh and was operated. Her left ribs and lung were removed. She had to be in the sanatorium for 3 years. It's heartbreaking to see people die.

”

- Aruna

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## MESSAGES OF HOPE AND STRENGTH

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My treatment went on for 6 years. The doctor told me that there was only a one per cent chance that I would survive. I took that chance and I was singing songs while entering the operation theatre. I told my parents, “I’m going to be back.”

- **Deepti Chavan**

Deepti Chavan, a guest on our episode, showed us how her willpower and inner strength led her to win the war against TB. We hope that the messages in this section give TB patients as well as other readers the courage to face adversity with self-belief and positivity.

“

I want to share my story, as I have never told anyone close to me (other than my parents). I was in class 9 (1990–91) and used to play soccer at zone level. But suddenly I started to feel pain under my left rib case. My parents took me to a doctor. He suggested perhaps I have typhoid fever so he treated me with typhoid medicine for 10 days which I used to vomit out after each intake. Then, my parents changed the doctor and he told me I have got TB.

I was lying on the hospital bed and I got cold sweats and my mum was crying. Then I thought I have to fight and win like it's another match of soccer. It's then that my real treatment started. I had to go to the hospital every day twice to take injections and had medicine continuously for about six months.

After that I was allowed to go to school again. I started to pick up the pace and played till national level and then university. Now I'm gonna help Operation ASHA so that they can help someone who could recover and lead a normal life again.

”

- Nishant  
Australia

“

I was diagnosed with tuberculosis when I was 13 years old. I had cough from several weeks but I didn't think it would be this severe so I basically ignored it. There was this one time I coughed blood and I was very, very scared, almost crying.

My brother rushed me to the doctor and he immediately told me to get an X-ray of my chest done. My family and I were shocked when the doctor told us I had TB.

I was very disappointed with myself because I knew what TB was but I still ignored my health and let this happen to me. My doctor gave me a course of meds and told me to follow it strictly and I did follow it.

Strictly following the medicine course and eating healthy helped me recover. Now I'm 18 years old, doing diploma in IT engineering and totally fine and healthy.

”

- Priyanca B  
Mumbai, Maharashtra

“

I live in USA and work in the healthcare field. Personally I have been diagnosed with tuberculosis. The way my case was handled by my state government was very appreciable. They not only treated me but tested the entire family who could have been in close contact with me. All the treatment testing and meds for the entire family and three more families that possibly could have been exposed to TB by me was given for free. I'd like to say that TB is a simple bacterial infection and is easily curable with prompt medication intake.

”

- Mili

“

I am a business owner in the US and 16 years back, an employee who was only 21 years old and had just come from India came down with a chronic cough and fever. OTC treatments did not work. I had a 6-month-old and a 5-year-old in the house. He did not have any medical insurance so I took him to the health department and had him take the TB test. He came back positive. I immediately took him to the hospital and the lung X-ray showed nothing but a black spot.

When they did a biopsy the outer wall burst open and his TB spread all over. He was isolated in the ICU unit. Thereafter I took care of him there and for another 2 years at home. All treatment was paid by my husband and me. Today he runs his own business and is healthy. This show sent me back on that journey we took.

”

- Manan Patel  
USA

“

My wife is a survivor of Abdomen TB and I wish to share her story with you for the benefit of all viewers. I cannot forget each and every day she went through during those days where she encountered severe pain near abdomen and she told me one day even that she decided to end her life.

I work at a bank and there was huge support from my boss, colleagues, family members which gave us lots to strength to withstand this trauma. Visiting a psychiatrist also helped her get ample sleep, elevated her mood and her urge for eating. I took her to various parks where she used to sit below a tree and I tried to connect her with nature which has a great healing power.

After 6 months of taking TB medicine, she was alright. After around a year she again developed sudden pain in her abdomen and we feared TB again. She was again hospitalised but it was detected as appendicitis. The fallout is her ovary is damaged at one side hence she may not have a child in her life. But I am happy that after the second surgery she was alright and doing well.

All this pain forced me to think beyond my family. Even though we had doctors, medicines and money, we could not stop her pain so I wondered how all those poor people are surviving this. From that day I became more concerned and helpful to all those needy people who may need my attention. I became a volunteer at a medical college and whenever any patient from my area seeks my help, I extend all possible help, both financial and non-financial.

This whole episode has given birth to a forum called ‘Nishabd Madhyam’, a medium of change which tries to help the needy. John F Kennedy once said that if a free society cannot help many who are poor, it cannot save a few who are rich.

”

- Jaydeep  
Bhubaneswar, Odisha

“

I want to share my experience about TB. I am 30 years old now and was affected by TB when I was 10 and again when I was 17. I didn't complete the full course of 1 year and was again affected by TB when I got married at 26. Because of my wife, I was able to get the proper treatment of 1 year and now I am fully recovered.

”

- Sandeep Sonskar

“

I was also an MDR TB patient when I was 14 years old. I took the TB treatment for 7 years! I am not able to express my feelings and pain but I totally feel blessed that now I have defeated the disease with my family's support.

”

- Priya

“

I got TB when I was in Class 10. I was fully treated. I became a pharmacist and I now work for TB patients in a government hospital in Delhi.

”

- Mahesh  
Delhi

“

I was unwell for almost a year and had undergone various treatments ranging from high fever medication to asthmatic medication before I was diagnosed with Koch's abdomen (TB in abdomen) which is considered a silent killer. Fortunately I was diagnosed at the last stage and with 18 months of medication I got completely cured of it. I really thank my doctors without whom this would not have been possible. We even had a baby after the treatment got over who is healthy and fine.

- Sandeep Iyer

”

“

I am a TB survivor. Jab mujhe first time pata chala TB ki bimari ka to mujhe kuch ajeeb laga lekin 4 months mein maine kafi hadd tak apni iss bimari per kaabu kar liya aur mujhe ummeed thi ki main jald se jald is par jeet hasil kar lunga. Un mahinon mein maine ek bhi din dawai miss nahin ki. Mera har subhe uth ke yehi ek bada kaam tha ki mujhe bhule bina dawai leni hai. Maine roz yoga karna bhi start kiya. Yoga se mujhe bahut madad mili aur sharirik aur maansik roop se fayda bhi hua. Main doosre patients ko bhi bolna chahunga ki aap haar mat maaniye, yeh rog lailaaj nahin hai!

”

- Vivek Anand  
Meerut, Uttar Pradesh

“

I am a dentist and I am a TB survivor. I was treated for a year. Both my lungs were affected but today I play tennis every day. So don't be afraid and take medication regularly. Support the patient, fight the disease, not the diseased.

- Dr Abhishek  
Ahmedabad, Gujarat

”

“

I can personally relate to the TB episode, as I had the disease and finished my treatment in January 2015. One of the lymph nodes in my groin area was infected and I got it operated and it was taken out. Next day it was taken for a culture test and it was confirmed I had TB, luckily not MDR, XDR or TDR. I am a temporary resident in London and from my diagnosis to treatment, everything happened at a government hospital here.

I was given two months drugs in my first consultation with the doctor so that I didn't have to come to the hospital every day. I had weekly / fortnightly blood tests though and the culture tests were repeated to see if I was still sensitive to the drugs. I am absolutely fine now apart from some aching bones which was one of the side effects expected to happen after taking 2000 tablets in 6 months! I am taking some supplements to overcome this and hopefully over time, this will disappear.

I think what helped me the most was my wife's support. I also had full support from my company manager and director. I was given 6 weeks off without hesitation, without having to worry about my work or losing my job. My doctor was also very knowledgeable and the nurse who was looking after me and my treatment was educated and kind to answer my questions throughout.

When I saw your episode, I felt relief because my treatment style was exactly opposite to the process which is being followed in India. For example, early diagnosis, proactive culture test of the lymph node, simultaneously checking if the bacteria I had was sensitive to the drugs I would be given, and so on.

”

- Prabhat Rathi

“

Last year, one of my roommates had TB but we roommates were very normal with her because she was already tensed due to the disease and its treatment. What I felt during this was that only love and care can give strength to the one who is suffering. By God's grace she is completely well now.

”

- Jharna

“

My hubby was diagnosed with TB in intestine very late. Initially he was diagnosed with Crohn's Disease and was treated for the same. As I took him to emergency due to severe stomach pain, it was found that his intestine has got perforated due to wrong diagnoses. The doctors said that doing surgery is dangerous but not doing surgery is all the more dangerous.

After surgery he was in coma for about four months and treating him for TB was very difficult as doctors told me that TB medication is mostly available to be consumed by mouth and not in liquid form. But they got some medicines in liquid form. I really appreciate the doctors who worked on my hubby's case so hard for almost two years. Now he is fine and working again.

”

- Veena  
Toronto, Canada

“

When I was about to appear for my class 10 board exams, I was suffering from TB. It was normal TB. But the pain and suffering was such that it made me lose concentration over my studies. Swelling on my neck, hair loss, knee pain, fever was making me lose my confidence. I had tablets for 6 months. But miraculously, my suffering ended and I have been fine. Zindagi mein kuch bhi ho sakta hai!

- Babul

”

“

I was suffering from spine TB (last stage) and due to wrong or rather overdosage of medication, I almost had liver and kidney failure along with low haemoglobin level. I was bedridden for 3 months and I am just 22 years old. Now I am fine and I would like to say that all TB patients should go to a proper doctor and never lose hope.

”

- Viraj

“

I am one of those lucky people who survived the first stage of TB. My treatment lasted for eight months. I am thankful to my doctor in Baroda, Gujarat who treated me during 1990–1991.

”

- Raj  
USA

“

I am also a TB patient since December 2013. I am taking my medicines properly and have a healthy diet too. I was so scared and weak, and was not able to be present in my class and give my second year B.A. exams. But now I am well and I am trying to continue my classes again.

”

- Umra

“

I am actually having TB of stomach which in medical terms is called Koch's Abdomen. Almost 8 months ago I was diagnosed with TB and I started the treatment in a private hospital. In 1 week I was cured but the doctor said that I have to take the medicines for months and the hospital bill was almost Rs 65,000. My dad was shocked listening to it but he paid it. At that time I was pursuing my engineering degree in Ratnagiri.

Then I came to know that I can get the TB medicines in municipal hospital for free so some of my expenses would be saved and fortunately municipal hospitals were near my home. After diagnosis in a municipal hospital they agreed to give me the tablets of TB as stated to me for free.

I completed my course of medicine for 1 year and right now I am cured of the disease and living a normal life. I also completed my engineering degree and I also pray to god that no one should ever go through this.

”

- Uday Desai

“ I came to India in 2010 from UK where I live and was diagnosed with TB infection (latent TB which means the bacteria in the body are inactive/asleep) in February 2012 immediately after my visit to India. I am completely cured now and live a very healthy life.

”

- Kamal Jain

“ 10 years back, I was affected with severe cold in lungs and the doctor told me it is TB. I went back to Thanjavur and took medicines for 6 months and was cured. Now I am living a happy married life and am pregnant also.

”

- Saniya  
Tamil Nadu

“ I was diagnosed with TB few years back and thanks to God that I had proper treatment. During that time my father-in-law who is a General Practitioner in India came to visit us. He came with me to the hospital for the follow-up. He was so impressed by the doctor, the way he explained the requirement of taking medicine on regular basis and gave me all the necessary information regarding the TB.

- Bimal  
London, U.K.

”

“

Aapko main ye batana chahta hoon ke mujhe bhi TB tha aur maine complete DOTS liye. Jiss doctor se main DOTS tablets leta tha woh doctor bohot nice hai. Ek baar unhe kahin jana tha to ek din pehle unhone apne peon ko bhej kar DOTS lene ke liye mujhe bulaaya aur mere DOTS kabhi miss nahi hue. Ye baat 2005 ki hai jab me 26 years ka tha. Aaj me 33 years ka hu.

”

- Sanjeev Kumar

“

I am an Indian citizen living in Europe. I was detected with latent TB. My family was also called for the TB test by the hospital because they were staying with me. Had I been diagnosed in India, I do not believe that any doctor would ever have thought of checking for latent TB through a test of the other members of my family. Anyway, by taking regular medication, and staying with my family, without spreading it to others, I am cured within 6 months.

”

- Shankar

“

I would like to tell you that my wife suffered from TB 4 years back. She was treated for 12 months and is now free from that disease.

”

- Abid

“

I already suffered from MDR-TB and have gone through minor surgery. But now I am completely fine. TB is totally curable with proper precautions and nutrition.

”

- Valji

“

I want to share that one of my close friends caught MDR TB while working in a general hospital setup. Our friends' group didn't outcast him and focussed on helping him recover.

”

- Dr. Prateek

“

My friend's wife is suffering from a tuberculosis clot in the brain. She was shifted to a hospital in Mumbai. The local doctors did not charge their fees as the said patient is the wife of an ex-defence personnel. Even the hospital stay for the last three and half months was at no cost. The way they took care of her is salutary. Their work is inspirational for others to follow.

”

- Shailesh  
Valsad, Gujarat

“

Hi, I live in the UK. I suffered from TB in 2006. I had a really bad cough. Doctor was saying just have Paracetamol. It didn't work. I got really fed up. In the end they did my X-ray and found out I had TB. And that's it, from then, a TB doctor was on my case. I used to take 12 tablets.

My mum came from India because I wasn't in that stage to do anything. My weight was only 40 kg. Here the treatment is really good. I still have scars in my lung. I am fine now. I have two beautiful kids now.

”

- Hardeep

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# IN CONCLUSION

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The messages that you have read in this booklet make it evident that we are currently facing the danger of a ticking time bomb in the form of tuberculosis. We may not realise it but this bomb can explode very soon if we don't take urgent action. In this fight against TB, either all of us will sail together or sink together. With the will to understand and engage deeply on the issue of TB prevention and cure, let us unite to make India a TB-free nation.

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