

I didn't think I'd have TB

By Lungi Langa



My name is Lungi Langa. I am a 24-year-old HIV-negative health journalist. I am living with TB. It sounds odd when I say that. But it's real.

Since the beginning of last year, I have been writing many stories of people living with HIV, tuberculosis and other illnesses. In my wildest dreams I never imagined that I would be that patient I so often interviewed. Being infected with a disease that I had come to know so well through my work terrified me and turned my whole world upside down. I was frightened, because I knew of so many people who sought treatment when it was too late, dying before they could be cured.

I had the classic symptoms - coughing for several weeks and night sweats. However, visits to clinics didn't lead to a TB test.

Nurses at Plumstead Clinic in Cape Town and Merebank Clinic in my hometown of Durban shrugged when I enquired whether a TB test wouldn't be a good idea and handed me bottles of children's cough mixture and antibiotics. They didn't believe I had TB.

After visiting Merebank and Plumstead in October, my coughing continued and got worse. Eventually my colleagues encouraged me to make an appointment with a private doctor even though I wasn't keen. I had been to the clinic and the sisters were happy that I did not have TB, what would the doctor find?

The sky was grim as I made my way to Newlands train station. It was October 28 last year, and I had a noon appointment with Dr Lee Miller.

By now I had diagnosed myself with every illness other than TB. I remember telling Dr Miller that I thought I had bronchitis.

"Do you have pain to your left?" she asked.

"Yes, especially when I cough," I replied.

"I don't think we should panic, but I want you to have a chest x-ray," she said after examining me. "Just so we can cancel out TB," she added. My head refused to believe I had TB.

Within a few hours Dr Miller had organised an x-ray at Claremont Hospital.

On my way back to work my cellphone rang. "You have TB, my darling," said Dr Miller.

The first thing I wanted to say was "That is rather absurd doc. I can't have it. You probably have the wrong x-ray". But there was nothing absurd about it. I had TB.

"Let me phone you back when I get to the office?" I said hanging up the phone. I felt nauseous, my heart was beating, it felt like the world was crumbling around me.

In that moment I had no hope.

At the office I saw missed calls from Dr Miller on my cellphone. I phoned her back just to make sure I heard her right.

"According to this x-ray both lungs, especially the right lung have been badly affected by TB. You need to start treatment straight away. Can you come and get a referral note from me?"

Dr Miller asked me to go home and stay there for at least two weeks in order to minimise the chances of infecting my colleagues.

I started phoning close friends and family I had come in contact with. I had been to Durban visiting my family a few weeks before and urged my family to have themselves tested. I pleaded with my sister to also take my daughter, Sthabile, who was two years old and living in Durban at the time, for a TB test.

I got home, still in disbelief – my head was spinning. I showered and wept uncontrollably for the first time. I could not believe that I was sick. The other thing that made it really tough was that I had exposed a lot of other people including Sthabile.

Dr Miller had ordered me to go to my local clinic as she was not allowed to treat me because TB treatment is only offered in the public health system. So I travelled to Plumstead Clinic early the next day. The nurses at the clinic made me wait before eventually telling me that they didn't attend to TB cases or referrals. They referred me to Claremont clinic.

Tired and scared I went straight to the clinic. I was desperate for someone to speak to me about my condition and make me feel better. At the clinic I was told that the nurse was out for the day and I had to return another time. This was my first realisation that the road to recovery was going to be a long one, one which would test my patience and resolve.

On Friday 30 November I went back to Claremont Clinic and arrived at 7.30am to be seen by a nurse. She glanced at the doctor's note and without seeing the chest x-ray she told me that although the doctor "claims" I might have TB she needed to confirm it with two sputum samples. She told me it would take 48 hours for the laboratory to check each sample and return the results to the clinic.

I gave her a sputum sample on the spot and returned the following Monday to give the second sample. I was told to come back three days later for the results. Five days since diagnosis and I was still not on any treatment. I was offered no counselling or information.

The clinic sister also didn't offer me an HIV test. When I requested a test, she said the HIV counsellor was not in and she didn't know when she was coming back. I returned home feeling disappointed and hopeless.

I decided on my own to quarantine myself in my room. I no longer cared what I had as long as it was a sickness that was known and could be treated.

On Wednesday I got a call from one of my colleagues to tell me that I was supposed to return to the clinic for my sputum results. She had phoned a contact she had in the city health department who contacted the clinic.

At the clinic the nurse gave me a hard time, demanding to know why I had told her superiors that I wasn't offered an HIV test (this was after my colleague made the call). She also said she needed to make sure that a person had TB first before putting them on treatment because TB treatment is complicated and people could develop resistance. She then simply said the four words that have changed my life forever: 'You do have TB.'

I didn't know whether to laugh or cry. The doctor had told me in a nice and polite manner that I had TB and here I was with a nurse who was clearly angry with me yet giving me my results at the same time.

I remember thinking at least I now know for sure and can start treatment, which I did and am still on to this day. The nurse explained that I would be taking the treatment for six months, until April. She advised me to religiously take my treatment or risk getting drug-resistant TB.

The nurse handed me a small plastic container filled to the brim with some of the biggest tablets I had ever seen. She ordered me to fetch water and carefully watched me as I tried to gulp it down six tablets. Only then did she sign my green treatment card. This was a process that was to occur daily for two weeks and it was one of the toughest times, feeling sick and tired and having to get on a taxi and travel to the clinic to swallow a pill in front of a nurse.

November 12 was a highlight when my colleague Nina, who also agreed to be my treatment supporter, took me to the clinic to collect my month's treatment. No more early morning taxis in the rain, no more harsh clinic staff, no more queues!

It took a long time for me to get better. In fact, I felt worse. My symptoms got worse. I had cough attacks, night sweats, depression and headaches. I got worried, thoughts of drug resistant TB started to scare me.

Although I was coughing, experiencing shortness of breath and feeling tired all the time I was at least on treatment and on the road to recovery. However, my daughter had still not been tested for TB.

My sister had taken her to a clinic in Durban where a nurse gave her one look and proclaimed she didn't have TB.

I knew I had to get her to Cape Town so she could be tested. In her first week here I took her to the clinic. The nurse did a TB skin test. Although it seemed painful Sthabile only cried for a few minutes. It was a great relief when her results came negative a week later.

I could never have lived with myself knowing I had given my child TB. She was then placed on a prophylaxis called Isoniazid (INH) which she will take every day until May.

Friends said I was overreacting, but I knew what it was like to have TB. To cough until I was out of breath, to be extremely tired the minute you wake up, losing your appetite. I wasn't going to let Sthabile experience that.

Taking my treatment has become part of my life. On weekdays I take my treatment at work. Nina reminds me to take my treatment a few minutes before starting work which makes it a lot easier. There are many days where I would forget to take it if she didn't remind me.

Looking back, I remember how I feared what people would think and what they were going to say once they knew I had TB.

For a long time I had known that people associated TB with being HIV positive. I did not worry about that. I was worried that they would not want to associate with me because I would infect them. Instead the people I told encouraged me to take my treatment and told me that TB could be cured.

My journey reminded me that there were many other people who continue to fall through the cracks of our primary health care system. Maybe some of them die without getting treatment because they can't even get a simple diagnosis which should determine that they need to be put on treatment.

I hope I can write stories to make sure they get the treatment they are entitled to. I had TB. I failed to prevent it, but I am cured. I am proof that we are all affected.