



## A PATIENT'S VOICE

## My TB story

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I was diagnosed with pulmonary tuberculosis on 3 June 2004, my only symptom having been a dry, nagging cough. I reported to my supervisor, who advised me to report to Occupational Health at the hospital. There I was informed that all PTB cases are handled at the Durban Chest Clinic (DCC) and that I should be there before 7h00 the following morning – ‘that’s when the doors close’. For those of you who don’t know, the DCC is situated in Warwick Avenue (not exactly the safest place in town) and parking was really limited (I had to park at the back of the building and walk to the front – I felt lucky to have my car and to not have been mugged or killed).

I arrived at the DCC at 6h45 and from then on it was just one queue after another. It took an hour and a half just to get into the clinic doors. I then had to fill in more forms before being sent into a little room with about 20 other people, all trying to cough up a sputum sample. If I had a ‘few’ AFB in my lungs before entering that room, I must have had a million when I left. Or at least that’s how I felt at the time.

From there I was sent into another room with a dozen more people, to have chest X-rays taken.

I then had to wait in a hall, full of sick people, for another two and a half hours before I was called to see the doctor. She checked my results, informed me that I had to start a 6-month course of TB medication immediately, answered my numerous questions and then sent me to the treatment area.

Here a nurse gave me the medication and explained the dosage and possible side-effects. I guarantee you, nothing she said could have prepared me for what I was about to go through. I was given medication for the week and told that I could pick up my supply for the next 2 months at the hospital where I worked. My next check up would be in 2 months’ time at the DCC, when my dosage would be reviewed.

## DOT – or not?

Before I go on to the nasty effects of the medication, let me tell you about DOT (directly observed treatment). The nurses at my hospital’s sickbay refused to give me my 2 months’ supply of medication. I was told I had to come in daily to the sickbay to

*I am a physiotherapist who was working in a government hospital when I was diagnosed with pulmonary tuberculosis. This is my story.*

take my medication. This is how DOT was being implemented at the hospital: I come in at any time, I don’t have to say anything to anyone, I take my medication in the treatment room where it’s kept, I take my card out of a box and leave it on the counter, and then I leave. The presence of my card on the counter will indicate that I have taken my medication, and it will be ticked for that day. If I know I’m going to be on leave, I can take the medication home for the duration of the leave; however, if I am sick and unable to be at work, I must drag myself to work and take my medication, and the doctor will then book me off sick. Please note – *at no point in time was anyone watching me to ensure that I actually took my medication*, so what difference did it make where I took it? Why couldn’t I have just have taken it at home?

To me this is totally ridiculous and not ‘implementing DOT’ at all. Besides, I am a health care professional and well aware of the consequences of not taking the medication. I don’t feel that I need to be ‘babied’ in terms of DOT. This is my personal feeling.

Having said that, and having been on TB treatment myself, I do understand why DOT is in place for people not in the health field. If I had not known the consequences of non-compliance, I can honestly say that after a few weeks I would have stopped taking the medication. So I agree – DOT is a vital system for people on TB treatment, but at the same time it needs to be implemented correctly.

## A daily struggle

For my first 6 weeks on the medication, every single day was a struggle for me. I was taking 7 tablets, 5 Rifamprazole (as my weight was above 50 kg), 1 pyridoxine (vitamin B<sub>6</sub>) and 1 maxolon, an anti-nausea drug that just did not work for me. My mild nausea gradually got worse until I was vomiting profusely. My last full meal for the day would be lunch, after which I took the medication and the nausea began. I was instructed to take the medication at lunchtime and then to be active. The irony was that the nausea and vomiting was accompanied by fatigue and malaise, and I couldn’t even have walked up two flights of stairs. The drive home at the end of the day was an effort because I was so exhausted I could hardly keep my eyes open. By the time I got out of the bath at night, the pains in my legs were so bad and I felt so miserable that all I could do was roll into bed and wait till I fell asleep. I longed for the next morning when I would be myself again – until lunchtime. In spite of all this, I continued to work.



I spoke to other physiotherapists, doctors, pharmacists and the people at the DCC. Nobody could tell me when I would start to feel better, just that I eventually would. In the meantime I was dubious – was vomiting daily for 6 weeks and feeling the way I did actually normal?

I was told that stress is one of the risk factors for TB, yet I don't think I've ever been as stressed in my life as I was at the beginning of this ordeal. I had to deal not only with the stress of accepting the fact that I was infected with TB, but also with the stress of all the 'closed doors' that I encountered after my diagnosis.

## Lessons to learn

My message today is simple. As health professionals we are *all* at risk of being infected, not only with TB but with every other disease out there, including HIV. According to hospital statistics, 15 patients had TB in the ward I worked in at the time I was infected. The majority of the 'please induce sputum' referrals we received were for patients who were suspected of having TB and not yet on treatment. I wore a mask, gloves and lab coat and took all the routine precautions, as you would with any chest patient. I got infected because those precautions are not foolproof. The masks and gloves we use are of poor quality. As many of you know, just putting them on can cause them to rip or tear. And when we are infected, there is no preferential treatment. In the eyes of our health care system, our education and qualifications mean absolutely nothing, and I think it's time we health professionals take a stand and do something about that.

I am writing this to highlight my dismay at the way health care professionals are treated and in the hope that my story will

set the ball rolling for the drastic changes I think are needed. I hope a set protocol can be implemented so that we are not obligated to obtain sputum samples from patients queried to have TB, and that we can refuse to treat TB patients who are not yet on treatment. I hope that the quality of the gloves and masks we use can be reviewed, as currently they do not provide adequate protection. And I hope that, being government employees, we health care professionals *will* get preferential treatment for illnesses/diseases contracted in the course of our duties. Finally, the DOTS system is vital in the fight against TB. *If implemented correctly*, it will ensure that patients successfully complete their treatment regimens and thus decrease mortality rates.

This was my story. Two years on, I am fortunate to have made a full and complete recovery. Many of the thousands of people who have been infected by TB since then have lost their battle. Looking back, not much has changed except the strength of the disease itself. In view of the latest outbreak of extreme drug-resistant tuberculosis, isn't it blatantly evident that we are losing this war? And it is a war that can be won! What are we as health care professionals going to do about it? Yes, we have an obligation to our patients. But if we ourselves are infected due to poor protective mechanisms and protocols, this will undoubtedly have a domino effect, negatively impacting on our patients.

I'm sure many other health care professionals before me have shared my experience. One voice may not be very loud, but I hope that at least my story will help prepare those who may be infected with TB in the future.