

Anna Biernat

## The diary of a consumptive

**“What? How come? Does the disease still exist?” were the common reactions of people when I told them what I suffered from. “Hope you’re not going to die like Frederick Chopin?”**

It flummoxed me at the beginning, a little pain in my chest, high fever the next day. The first visit to the clinic, auscultative examination that did not reveal any incriminating evidence of carrying the legacy of a disease that had killed a third of Europe’s population in the 17<sup>th</sup> century. Even the doctor was confused and diagnosed ‘cold’.

Anti-flu tablets neither helped the pain nor the fever. Another visit to a clinic. The doctor this time was more careful: measured the blood pressure, had a look at the throat and even checked up the breasts. Still nothing sensational, as he diagnosed pharyngitis this time. Strong antibiotics (Augmentin), two syrups, chewable tablets for the sore throat which was not quite sore, paracetamol for fever.

Obviously I had something more serious, as an excruciating pain under the right breast pierced my sleep in the middle of the night two days later and left me exasperated. At 6 in the morning I was the only patient in the ‘night’ clinic, a vexed nurse who filled in a card wearily, told me to wait in the corridor. Fifteen minutes later a sleepy doctor called me in, I explained my rather sorry state, and how even antibiotics did not help. “Abdomen soft, non-operational,” he pronounced.

“But the chest pain?” I asked.

“It may be a gall bladder inflammation,” he said. “You should get an abdominal ultrasound done.” For which, I needed a referral from my family GP. Else pay for it.

The family GP, a paediatrician, performed all the standard clinical examinations (throat, auscultation, abdomen, blood pressure) and admitted he had no idea what it was.

“Could be something related to the lungs or the liver or the gall bladder. You must go to the hospital for a proper examination. I will give you a referral. The long weekend is coming and we will not be able to help you,” he said.

At the infectious diseases ward of the university hospital, the doctor was visibly annoyed to see my ‘referral’. He sent me for a chest radiograph and blood test, but not before calling up my family doctor and expressing his displeasure with the referral - on what basis, was I referred to the infectious disease ward without any examinations and tests results.

The X-Ray showed some white bones on a black background, some pouches here and there. Quite illegible to me, of course. But the writing below wasn’t. “Suspicion of tuberculosis” it read.

“Tuberculosis? What the hell? Why me?”

“Do not worry, it could also be pneumonia. Blood tests came out fine. We found a source of pain: a pleural effusion. You must consult the pulmonary clinic,” the doctor tried to calm my nerves.

Yet another set of tests at the pulmonary clinic. I was told even further tests were needed. “There’s a pulmonary cavity in your right upper lung lobe. It is characteristic of tuberculosis.” Unsettling enough.

**The fourth day in the hospital.** More pictures of the chest, computer tomography of the lungs, more blood taken for testing. Still no clear diagnosis. A positive result (2 cm swelling) tuberculin test, but no one’s ready to commit, and I am told, it “neither confirmed nor excluded TB.” Funny language that!!

By the time I was almost an exhibit, a popular figure of speech. A long weekend drew in Poland, sending most of the senior doctors to vacation and other more interesting places than the hospital. Only a few change doctors were managing the hospital and one would diligently show up every morning after breakfast. May be to gather better clinical experience!

My visitors, thanks to Wikipedia and online health manuals, come up with revelations. “I’ve heard that TB is curable, so do not worry. The treatment takes a long time though, even up to a few years,” a friend said. “I have read that the mycobacteria do not like the sun. Good that your bed is right by the window,” my mother announced.

**Boredom as hell. The seventh day in the hospital, a bronchoscopy.** The technique’s about inserting an instrument into the airways, a rather unpleasant exercise, but fortunately enough, did not last long. Result would be two days later, I am told.

A more charitable friend lent me a wireless modem for Internet access and I also read Wikipedia: “Increased risk of tuberculosis concerns: AIDS patients, drug addicts, alcoholics, people with impaired T cell-dependent immune system, homeless and malnourished, immigrants, persons over 65 years old.” Surprising indeed because I could not, in all magnanimity, fit myself into any of these categories. I am 26 and healthy, what’s more, as a child I was vaccinated against tuberculosis.

But I was in august company, the Internet told me, some silver living at least, in the same league as Honore de Balzac, Anton Chekhov, Franz Kafka, Moliere, Friedrich Schiller, Amedeo Modigliani, Frederic Chopin, Cardinal Richelieu, Eleanor Roosevelt, George Orwell, Niccolo Paganini. Thinkers, artists, poets, authors, musicians.

It might have come as a shock to Europeans, my family members, friends, ears unaccustomed to hear about it, eyes unfamiliar in reading about it in newspapers. But it does exist and kills a sizeable number of people every year around the world. Europe also, at one point in history not too distant, had fallen prey to tuberculosis. Shrouded in myths and misconstrued notions at the beginning of 17<sup>th</sup> century, people imputed it even to vampires. Red eyes, pale complexion, weight loss, low body temperature and haemoptysis – what else it probably could be?

And it was a disease of the talented but poor, intelligent but idealistic – authors, poets, painters, musicians – across continents, across countries. The romance and reflections were scattered through literature and society, the disease linked directly to creativity.

When in the late nineteenth century Robert Koch discovered the mycobacterium tuberculosis, there were new hopes of eradicating the epidemic. In 1921 the vaccine was used for the very first time and 25 years later the first effective medicines for tuberculosis were introduced.

Doctors, despite admitting that the number of TB patients was growing every year in Poland were intrigued by my case. Everyone asked: "Where did you bring it from?"

The most likely source seemed my stay in India for 10 months. According to the World Health Organisation, India accounted for one fifth of tuberculosis cases worldwide, or two million annually. Almost half of the patients suffer from the active pulmonary TB which means they have the ability to infect others, and for about 330,000 the disease proves fatal. In the European Union in 2007 there were a total of just over 80,000 cases of tuberculosis reported with the most (25,000) from Romania. In Poland, every year around 9,000 people fall victim to the disease.

According to the WHO, one third of the world's population is infected with TB bacillus, but only 2-3 percent of these people would develop symptomatic tuberculosis. In the remaining cases bacilli stay dormant and the illness may occur only after even several years. Or it may never. This happens in only 10 percent of all the infections. The greater resistance of the organism, the less chance of developing the disease.

**The 10<sup>th</sup> day in the hospital.** Regular morning visit by my doctor, and some mixed news. "Yesterday it seemed that you could go home soon. The basic tests showed no mycobacteria. Unfortunately, today we received the results of genetic probes and they proved positive," he said. It seemed there were indeed a few mycobacteria floating in my lungs, not enough to infect others but adequate to damage my lungs.

But there was elsewhere. The TB medicines were apparently not readily available in Poland. "We can't let you go home unless we're sure you have these medicines," the doctor said.

Production of the primary anti-TB medicine was stopped by Polish pharmaceutical company Jelfa in the beginning of the year. Stocks of medicine were bought by hospitals and warehouses were empty. It was the same story with the Czech product, Nidrazid as well.

Patients with tuberculosis in Poland are eligible for compulsory, free treatment. Unless one is highly infectious, treatment could be continued at home. But then, "We can not let you go home, with no certainty that you will have a guaranteed supply of Isoniasid. The best solution would be to buy these medicines abroad. Meanwhile, we will send the request to the Ministry of Health to import the drugs for you," I am told.

My personal search begins. A Czech friend's mother has got a pharmacy in Brno. They have the missing medicine. The Package Price: 7 euro.

There were too many questions I needed answers for. "How long will it last? Can I do sports? Will I be able to work? Can I drink alcohol? Kiss men?"

**The 13<sup>th</sup> day in the hospital, news about my illness has spread far and wide.** Friends are cautious in expressing their affection during the visits.

During the next morning visit by the doctor, I bombard the questions. “Since the Mann’s “Magic Mountain” a lot has changed in the treatment of tuberculosis. The most important part is to take the medicines regularly for at least half a year and taking care of the liver. No fried food and no alcohol! You will have to have regular medical checks. You must rest a lot, no effort and stress, at least initially. Avoid the sun. Kissing is allowed and safe as long as you take the medicines. Let me know when you get the Isoniasid. We will let you go home then,” he said.

While making the arrangements related to the shipping of the medicines from the Czech Republic, my aunt called me with some good news. In a pharmacy in Klaj, a little town near Krakow, her friend found what may well be the last package of Isoniasid in Poland, 500 tablets, sufficient for 2.5 months. I’m saved! I can go home!

At home, every morning I have to swallow 13 tablets with three glasses of water. TB medicines, liver protecting drugs, vitamin B. I sleep 12 hours a day but still feel tired. Will this feeling remain throughout the whole period of treatment? A friend from Turkey, who also suffered from TB a few years ago, says he lost 15 kg. I didn’t lose any weight yet. However, I find no pleasure in tasting food. I eat because I have to.

The doctor of the district pulmonary clinic who now treats my case filled in a special TB patient booklet and was relieved when the necessary supply of Isoniasid could be assured. When asked about the need for examining my family, with whom I live, he did not give a definitive answer.

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*The article, originally in Polish, was published in Poland’s biggest selling weekly newsmagazine “POLITYKA” (<http://en.wikipedia.org/wiki/Polityka>), issue number 31 (2716), 2009-08-01, page 80-81.*