

2: DIAGNOSIS

“Coughs and Sneezes Spread Diseases!”

(Anon - Ministry of Health 1942)

In section one we heard that TB is a disease spread by bacteria when an infected person with active pulmonary TB coughs. It can also happen if someone infected with tuberculosis sneezes, shouts, sings and so on (but probably to a lesser degree).

TB INFECTION AND TB DISEASE

TB infection and TB disease are different. TB mycobacteria can live in your body without making you ill.¹ This is called TB infection, or *latent* infection and is non-infectious. Normally, your immune system can trap the bacteria and stop them from making you ill. However, sometimes the organisms break away from this trap and spread to other parts of the body. When this happens the actual disease can develop. About 10 % of latently infected individuals go on to develop TB disease at some time in their lives.² However, the risk is higher for someone with HIV.³

You can get TB disease in all sorts of places in the body, not only the lungs. Unfortunately it can occur almost anywhere.⁴

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When TB isn't in the lungs it is called *extra-pulmonary tuberculosis*. If a person has TB elsewhere in the body other than the lungs or throat they are not infectious.

However, it is possible for bacteria elsewhere in the body to travel to the lungs making the person infectious. This may happen if the TB is left untreated or if the treatment regime isn't followed properly.

WHAT ARE THE SYMPTOMS OF TB?

The symptoms can manifest in a variety of ways, but few people will have all of the symptoms mentioned here. It is important if you develop these symptoms that you see a doctor, particularly if you have had TB before or are known to be latently infected. If you are on medication and these symptoms develop you should tell your TB specialist. The medication you are taking may not be working properly, and they may need to change the drugs.

If you have TB infection you will not usually feel ill. If you develop TB disease you may feel weak and tired. You might start to lose weight: in the past TB was called 'consumption'. People became 'pale and interesting', if you like. This look was thought to be attractive in the eighteenth and nineteenth centuries; the consumptive poet was something of an icon in the art world. The disease had curious romantic associations.

If you have TB disease you may also lose your appetite. You might develop a fever, though heavy night sweats are now uncommon.

With pulmonary TB you may get any of the symptoms above accompanied by a cough. You may have chest pain and might be coughing up some blood or blood stained sputum (phlegm). The medical terminology for coughing up blood is *haemoptysis*.⁵ You may also feel short of breath. Symptoms vary depending on what part of the body is affected. Left untreated these symptoms could get worse and put you in danger.

HOW IS TB DIAGNOSED?

TB was originally screened for prior to the BCG vaccination programme in this country using the so-called tuberculin skin tests. These are rarely of diagnostic value on their own because people who have been vaccinated usually produce a positive result. Nevertheless it is useful to review the nature of these tests. There are several types of skin test, two of which are the Heaf test and the Mantoux test.

The Heaf test is preferred for mass screening especially where the vaccination programme is not as prevalent as in the UK. Tuberculin is smeared on the skin and small puncture sites are made. The test is usually carried out on the inside of the forearm. It doesn't really hurt and doesn't usually scar. The test can then be read after seven days to grade a negative or positive response.⁶

The Mantoux test is very similar, except that a single injection site is made into the skin in the same place as the Heaf test. A stronger strength of tuberculin is used and a result can be measured after 48-72 hours to grade a positive or negative result.⁷

A positive result means that you have reacted to the TB protein. It does not necessarily mean that you are going to become infectious or have the active TB disease. However, your TB specialist may decide to put you on medication as a precaution to stop you from developing TB disease. This is termed *prophylaxis* i.e. taking medical action or giving treatment to prevent development of disease.⁸

A negative result would suggest that, at that time, you do not have TB. This is not conclusive. The test may be falsely negative in a person who has been recently infected. It usually takes 2 to 10 weeks after you have been exposed to a person with TB disease for the skin test to show a positive result. In addition, if your immune system isn't working properly this can produce a negative test result.⁹

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Chest X-rays are also used to assist in the diagnosis of TB. Areas affected by TB appear as white spots which may be cavities, and there may also be some abnormal shadowing. However, as with the Heaf test, if a person's immune system isn't working effectively, the chest X-rays may be misleading and further investigation may be required.¹⁰

I mentioned in the first section Robert Koch's method of staining TB bacteria which enabled their visualisation for the first time. For this test to be undertaken the patient needs to give samples of sputum. This then provides the basis for two tests. The first (and quickest) is a *smear* test. The sample of sputum is looked at under a microscope to see if any TB bacteria show up after staining and washing. If you are smear positive, TB bacteria have been found and you may be infectious.

The result of the test is then graded in terms of 'plus's' (+ to +++) indicating low, medium or high amounts of Acid Fast Bacteria. The higher the result the more infectious you are likely to be.

If you have TB disease, your TB specialist will want lots of sputum (they get very excited over it!). He can then monitor whether your treatment is working by looking for acid fast bacilli in the samples that you have given. You will find that your smear results get better as the TB bacteria are killed by the drugs. Eventually, the grading of the smear test will indicate that you are no longer infectious. This will only happen if the medication has been taken according to your doctor's instructions.

TB is a complex subject. A negative smear test result doesn't mean that you are cured. It simply means that you are no longer infectious. In addition, a TB specialist will want to carry out a second test called a *culture* test i.e. attempting to grow TB bacilli under laboratory conditions over a period of time; this usually takes about 6-12 weeks.¹¹

If the test is positive it means that TB bacilli are still present and treatment needs to continue. If there is a negative culture result, your TB specialist will want to carry out further cultures before he is satisfied you are cured.

CONTACT TRACING

If you have been found to have TB disease, your doctor will notify the Public Health Laboratory Service. This service monitors diseases like TB to see how they move around the population. It is this body which has produced evidence for the increasing incidence of TB in the UK.

TB is one of the so-called *notifiable* diseases. These are diseases of an infectious nature which a doctor is required by law to make known to a health officer or local authority.¹²

Your doctor may need to test people you have been in contact with to see if they have also been infected. Usually this will be confined to close contacts such as your family and people that you live with or see regularly.¹³ You may be asked for a list of these people. This is particularly important for people who might be immuno-compromised.

DIARY: DIAGNOSIS

We will now move on to consider my personal experience of tuberculosis. Just a note of caution before we proceed: some of the diary's content is quite frightening. My aim is to inform rather than scare you, and in any case there is a happy ending!

I was infected with multidrug-resistant tuberculosis in the first few of weeks of April 1995. I didn't know I had been infected at the time. Indeed, I was just getting on with my life. I didn't have an inkling that anything was wrong until two and a half months later.

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TUESDAY 27TH JUNE 1995 I have been getting pains in my chest for the last few days and they are getting worse. I have never known pain like it. It feels unusual, as though my lungs are sticking to my chest wall. I don't know what is wrong with me. I'm supposed to be going out with some friends tonight and I'm really looking forward to it, but I think I'll have to cancel because I feel too tired. All I've done today is lie down, but I don't feel like I've got the flu. I'm becoming really aware of the way I breathe, and I can't stop thinking about my chest. It feels so strange. I'm not going out.

WEDNESDAY 28TH JUNE 1995 I feel hot and I'm taking my temperature regularly. I am having intermittent fevers of about 39.5° c, particularly last night. This is very high. I still have odd chest pains and they are constant now. I have decided to go to the doctors and tell them exactly how I feel.

The doctors have taken a chest X-ray and asked me for a sputum sample. This will be induced sputum. They want me to inhale in a vaporised salt water solution and cough it out. They can then test the sample for signs of infection. There is a chance I might have an AIDS related pneumonia called 'PCP' (Pneumocystis carinii pneumonia) which is relatively easy to treat. If it is this, it will explain my breathing difficulties.

FRIDAY 14TH JULY 1995 I have decided to go back to the HIV organisation where I am working as a volunteer. I'm so hot, but my chest feels a little better. I'm so bored with just laying around. There is so much going on at work, and I'm feeling too guilty to just lay around. I'd also like to go out for a drink with my friends after work.

WEDNESDAY 26TH JULY 1995 A month has

passed since the pains in my chest started. I returned to the clinic for a check up. I talked with my doctor for a while and he asked me how I was feeling. I told him that I felt a bit better. I can't have PCP because he would have said something. I'm still feeling odd and tired, but I've been working late nights on my book. I'm planning a break with my partner when I have finished the book. I haven't decided where to go yet. I don't care, I just want a break.

THURSDAY 27TH JULY 1995 Today I'm finishing my book and I'm looking forward to it being published. I feel a real sense of achievement. I'm also looking forward to going on holiday. As I wrote the final page, I had the feeling that three years of work was coming to an end and I got really tearful.

The telephone rang and my partner told me that the hospital were trying to get hold of me urgently. I was quiet for a moment. Having PCP wasn't that bad and I didn't feel that unwell, just a bit tired. I started to feel a strange sense of dread.

I telephoned my doctor straight away and he told me that they had grown something called 'acid fast bacilli' from the induced sputum sample that I'd given back in June. This meant nothing to me until he said that I may have TB and needed to go straight back to the hospital. I went cold. Where the hell had I caught TB from? I didn't think it even existed anymore.

I put the telephone down. Although I'd been calm on the telephone with the doctor, I felt panic welling up inside me. I told the people in the office what I'd been told. The situation was so odd. No one knew what to say to me at first. I realised that they too had been at risk. For nearly three months I had sat there with them. I started to cry. I felt so guilty; TB but how? It was so Victorian. Had I known that I might have been putting people at risk, I would never have gone back to work. But people just snapped into gear again and helped me to pull myself together.

By the time I'd packed away my things, my partner had arrived in the car to take me to the hospital. I didn't know what to say. I felt like I was watching through a window. Someone hugged me, I really needed that hug. Being rejected would have devastated me.

My partner took me home first so that I could grab a few things and make a few telephone calls. I rang my mother first and tried to explain to her what was happening, but I didn't know quite what to say. She had been to see me a short while back. I didn't know how infectious I was, but I felt the need to tell her that she may have been at risk. I also rang a couple of other people, briefly filling them in on what was happening. There were so many questions that I couldn't answer for them...I just don't know what is going on.

We made our way to the hospital, and once on the ward. I was put straight into a side room on my own. I waited for a couple of hours; the whole situation felt really distant, as though it wasn't happening to me. Occasionally a nurse would poke her head around the door to see if I was OK. I felt so guilty, but I didn't know why. Eventually my doctor came in and tried to explain to me what was happening.

It had been decided that I would be placed in an isolation room. This was being prepared for me as we spoke. I didn't know what to expect and I was frightened. All of the images of isolation I had seen on TV and at the cinema flashed through my mind.

The doctor tried to get across the gravity of the situation, but said I should be OK. I was finding this confusing. They suspected that I had TB, and I was being put into isolation as a precaution whilst they did further tests. I felt they knew that they had to do something positive quickly, but seemed as surprised as me. The doctor compared the situation to what had happened in America in the recent past and kept stressing the need to halt

any potential epidemic.

What have I become - a bomb ticking away? What about the person who had infected me? In the meantime, they've asked me to write a list of everyone I have been in contact with since April 14th 1995. How could I do this? I had been to restaurants, on the tube -my head started to whirl. Were things that bad? Again I felt as though I was watching all of this on television. I wanted it to stop, but I knew it wouldn't.

I made my own way to the ward where I was to spend my time in isolation. As we walked my partner joked that the nurses may be waiting there with a cattle prod to make sure that I didn't come too close. It was an awkward attempt to make me laugh.

I was led down the corridor to the room where I was going to stay. I sat down on the bed, and the door hissed as it closed behind me. I was in isolation. What did this mean? Could I see anybody? I remembered the hug that I'd had as I'd left work. I could do with another. Human contact feels so important. Christ.

The walls of the isolation room are pink, and a picture of a dove is hung opposite the bed. When I arrived in the room it had no curtains. It is standard infection control procedure to remove them when someone vacates a room. I was told that a new set would arrive today, but they haven't arrived yet. I wondered if they would. How do I feel? I don't really know. Doctors are so used to this sort of thing, but I'm not. I need it explained to me, but it's difficult to take on board what they are saying. It must be the shock.

I'm feeling a bit hemmed in. They have told me that I can't leave the room until I'm told I can. I feel a bit like I've been a naughty boy. That's what my mother used to do with me when I was young... "Go to your room and don't come out until I tell you to." Still, I suppose it's better than "Wait 'til you father gets home".

That always meant big trouble!

When people come into my room they are wearing masks. It just seems to add to the surrealism of the whole situation.

FRIDAY 28TH JULY 1995 I am being given anti-TB treatment as a precaution whilst they do further tests to confirm the diagnosis. The needle that they put in my arm to give me intravenous medication felt raw this morning. The vein collapsed and now nothing will go through it. The thought of it - a vein collapsing - it makes me shudder. (They removed the needle and replaced it later in the day and the IV TB therapy was recommenced.)

My first meal arrived...Yuk! I remembered how much I hated hospital food. I'm a good cook and really miss great food. Each time I've been in hospital in the past I seem to have lost weight! On previous occasions I have got friends to bring 'edible' food in for me. They say I'm fussy and that hospital food is good for me. I have asked them to bring stuff in away. I certainly don't want to starve. My friends can eat the hospital food if they want to!

When my friends finally arrived they were wearing masks, plastic aprons and gloves. It felt strange having people I know wrapped up in this way. I could only see their eyes, and their speech was muffled. It made me feel tearful and guilty again. My friends felt initially awkward with the masks on, especially when it came to talking and smoking a cigarette. I offered to cut a hole in the mask for one friend so she could have one! This made us all laugh and things felt a little less awkward from then on.

Smoking, thank goodness, is permitted in my room. It would be completely unbearable if I couldn't smoke. It felt odd that I might have TB, but was the only one who could smoke! I wasn't sure if I should, but couldn't help it. I missed seeing everyone's faces as

we talked. It is funny how much we read into a face and not just the eyes as lots of people seem to think.

SATURDAY 29TH JULY 1995 The days seem to be blending into each other and I am finding it difficult to tell on which days events are happening. I am so bored and wish I was writing my book to pass the time. I've decided to dedicate more time to my diary so that I can really keep track of what is going on. At least I have something to occupy my mind.

I'd noticed that my dreams were becoming confused with reality. I would wake up thinking that I'd been outside, but I knew that that wasn't possible. I think this is because of the medication I am being given. It feels very strong.

SUNDAY 30TH JULY 1995 I still don't have any news on the further tests they are performing on my sputum sample. I find this quite annoying. The nurse keeps telling me that the results will come tomorrow, but tomorrow never seems to come. I know they are busy, but because I am in isolation it is all I have to think about. Each sample I have given for a basic smear test for TB bacteria has come back negative. This surely has to be good news. I may still have TB, but hopefully I'm not infectious. They have told me that if things stay like this, and if I don't have a fever, I can go home. If I do develop a temperature, or if a test comes back positive, I would have to stay. If the latter were the case, I would have to produce three negative smear samples with no temperature for at least a week before I could go. It feels like a bizarre game; I'm glad I'm writing all of this down as there is a lot to understand.

MONDAY 31ST JULY 1995 The good news is my sputum samples are coming back negative at the moment: I'm not infectious to others at present. This eases my mind as I think of

my friends. I hate the colour pink.

The TB drugs are doing strange things to me, and I feel ‘spaced out’ at times. I haven’t had a fever or a positive smear for a week. I wish I could go home.

WEDNESDAY 2ND AUGUST 1995 I woke up this morning having had one of the worst night’s sleep ever. It’s odd - I usually sleep relatively well. I lay awake most of the time trying to piece together what was happening to me. A note had been placed on my bedside table written by my doctor. It said that “guidelines we re not written in stone”, and that I had given negative smear tests for a week and that this meant I may be able to go home. It appeared I wasn’t infectious. I was so happy that I was almost certainly not a danger to others: even if I had TB, it didn’t seem to be active.

Eventually, a junior doctor came to see me and told me I could go home, although I would have to wait for the TB drugs they were giving me as a precautionary measure. Did that mean I could walk out of the room there and then? She paused for a moment - she couldn’t see why not.

She left the room and I stood there thoughtfully, almost as if I didn’t want to leave. I’d become used to the close confines of my room. I pondered momentarily over the pyjama bottoms that were far too big for me and ran through the door.

The heat hit me; I hadn’t realised that everyone else was suffering a heat wave. My room had been air-conditioned and the temperature hadn’t changed much. For the first time in a week I made my own cup of tea. Cups of tea were virtually the only thing that I asked for when I pressed the red call button for the nurses. I sat in the day room with other people. How fantastic to be around people again. However, not all of my news was good news.

A nurse had to give me some information before I left. He came

into the room when I was celebrating my freedom, and broke news to me that was going to change my situation dramatically.

I couldn't believe what I was being told. As a precaution, I was to stay away from all people that I knew to be HIV positive for at least two months, at which time the situation would be re-evaluated. I was devastated. Most of my friends were from the HIV organisation where I worked, and my partner was also HIV positive.

I was so desperate to spend time with people I knew after being alone, but I couldn't. Did I really have to stay at home for two months and not see anyone? It felt like I was going from isolation in hospital to isolation at home. Once again I felt disorientated.

By the main entrance of the hospital I sat on the floor and cried. I was so relieved to be out and (presumably) uninfected, but at the same time devastated at not being able to see my friends at this trying time. I knew, however, that it was a restriction that had to be endured.

TB TIPS: DIAGNOSIS

- TB is curable - if you feel you have been exposed to TB by someone else don't panic!
- If you are in contact with someone who has been diagnosed with TB you should tell your doctor so that he can carry out appropriate tests to see if you need treatment.
- Depending on your personal circumstances, your doctor may feel it is appropriate to put you on some medication to prevent you from developing TB - even if you appear uninfected.

- If you develop any of the symptoms mentioned in this section viz: persistent cough, blood stained sputum, fever, night sweats or weight loss - don't leave anything to chance - get a check up from your doctor. The sooner you are treated for TB disease, the sooner you will be cured.
- The symptoms of TB vary from person to person. Any combination of the symptoms mentioned above are worth having checked out.
- Sometimes you will have to wait a long time for test results. It serves no purpose to torture yourself during this time. Try to be patient. It will probably be good news.
- If you don't understand what a doctor is telling you, ask again...and again if you have to. Don't be intimidated by them - they are human beings too! Sometimes, because they understand their subject as well as they do, it is easy for them to assume that you understand it too. Take a notepad if necessary.
- Take a friend with you when you go to see the doctor. It helps to be able to talk over what you have heard with someone else you know well. It also helps them to know what is happening to you.
- If you are found to be latently infected with TB remember you are not infectious; only about 10 per cent of people go on to develop TB disease. However, if you are immuno-compromised in any way you may be more at risk. Talk to your doctor about this.

- You may have to spend some time apart from people who may be considered vulnerable. Having to spend time away from friends during a time of need can be hard, but it is a necessary precaution. It is better to be safe!
- If contact tracing is initiated, disclosing names of people you have been in contact with may be embarrassing and awkward - again it is best to be safe. You never know, one of the people on your list may have infected you and may need help and treatment themselves.
- Nurses won't mind you talking to them if you need help. It is part of their job and they are often easier to communicate with than doctors and are generally more approachable.