

## **3: TREATMENT**

*“Venienti occurite morbo - Confront disease at its onset.”*

*Persius (Antus Persius Flaccus) AD 34-62*

Tuberculosis treatment falls into two categories: *preventative* i.e. trying to stop people from getting TB in the first place, and *remedial*: treating the disease when it occurs.<sup>1</sup>

### **TB TREATMENT: PREVENTATIVE**

The two most important preventative measures for tuberculosis involve the BCG vaccination and the chest X-ray, although the latter is not generally undertaken on a mass scale in the UK.

The BCG vaccine is generally given at school between the ages of 10-14, a few weeks after a Heaf test; it may leave a small scar. The BCG is given routinely in the UK. Some practitioners prefer to give the BCG vaccination at a very young age. Babies only a few weeks old may be vaccinated if they are born in areas where TB is more common, for example the inner city areas.

Its safety is undisputed; the effectiveness of the vaccine itself is, however, a contentious issue. In the USA, vaccination with the BCG is not a routine undertaking as its usefulness is felt to be

uncertain. In addition, because the BCG vaccine contains ‘tamed’ and safe bacteria, when a vaccinated person is later tested for TB with a Heaf test, they get a positive result as mentioned above. The American fraternity believes that this impairs the usefulness of later Heaf testing.

When asked about the different attitudes of the UK and the USA towards the BCG vaccination, senior medical officer Dr Jane Leese from the Communicable Diseases branch of the Department of Health said: “The Americans are not convinced of the benefits of BCG and believe it interferes with the tuberculin skin test as a diagnostic aid, and it is true that most people will develop a low-grade positive skin test response after BCG. In the UK we do not find this a problem. It is also true that trials of BCG have shown widely differing effectiveness - in general the nearer the tropics the less effective it seems to be and the reason for the variation is not understood.”

The BCG vaccination remains an area of debate in terms of its effectiveness - many people vaccinated still go on to contract the disease. A mass vaccination programme can also have another adverse effect: people may fail to recognise that their symptoms are caused by TB because they have been vaccinated against it, and assume that they are immune.

## **TB TREATMENT: REMEDIAL**

If you are diagnosed with TB disease your doctor will want to put you on medication to treat it. There are a variety of drugs which are used in combination with each other. If you have ‘standard’ (for want of a better word), ‘fully sensitive’, or uncomplicated TB, you will usually be given a combination of the following:

- **ISONIAZID [INH]** *A cheap and highly effective drug. It will always be given if you have sensitive tuberculosis, unless there are specific reasons for not giving it to you. It’s*

*only common side effect is peripheral neuropathy (tingling and numbness in your fingers, hands, toes or feet which can sometimes be quite painful). This is more likely to happen if you have diabetes or a problem with alcohol or your kidneys, or if you have HIV. Pyridoxine (vitamin B6) is given in high doses to try to prevent this.*

*Special blood tests will be carried out by your TB specialist to ensure that hepatitis, which is a rarer side effect, doesn't occur. Mental health problems are even rarer. Having said all this, most people tolerate this drug rather well, though it is worth mentioning some people experience an acne-type rash. It is very effective. Isoniazid is given in combination with rifampicin.*

■ **RIFAMPICIN [RIF]** *Like isoniazid, this drug is a key component of the anti-tuberculosis regime. It will always be included unless there is a good reason not to. Occasionally, the liver has problems coping with this drug, and you are more likely to suffer from this if you have previously had liver disease. As with isoniazid, your doctor will want to take blood tests to ensure you are tolerating the drug.*

*Rifampicin can cause other minor side effects. For example, it might stain your urine, tears, saliva or sperm an orange colour. This may seem weird at first, but it is not something to be alarmed about. In addition, you shouldn't wear soft contact lenses as they may also stain orange. It might also make you more sensitive to the sun. Use a sunblock!*

*Female patients may find that it makes the contraceptive pill and implants less effective. Women should talk to their doctors about alternative birth control measures.*

*If you are taking methadone for drug dependency, it should be noted that you may require an adjustment in your methadone dosage. Rifampicin can change the way the*

*methadone is absorbed: you may have withdrawal symptoms, and your dose will need to be re-assessed.*

- **ETHAMBUTOL [EMB]** *This drug is usually included in the treatment regime for the initial two months of treatment if you are unable to take Isoniazid. (Incidentally, isoniazid resistance is the most common: this is not surprising as it's one of the most commonly prescribed anti-tuberculosis drugs.) Side effects of ethambutol are largely confined to visual disturbance. Colour blindness and restriction of the field of vision are common when excessive doses have been taken, or if the person taking the drug has kidney problems. For this reason, it is not used for the treatment of young children*

*Your TB specialist will carry out tests for colour blindness, much like the ones that you had at school. A number made up of dots, hidden amongst dots of appropriately contrasting colours. This is called the 'Ishihara test'. Ethambutol dosage is worked out from your weight. Your doctor may adjust the dose if you are having visual problems or may change the drug completely.*

- **PYRAZINAMIDE [PZA]** *This drug is useful in the treatment of tuberculosis meningitis because of the way it penetrates into the brain substance. There is a 'barrier' around the brain which many drugs find hard to pass through. Liver problems may also occasionally occur with this drug.*

- **STREPTOMYCIN [SM]** *This is given in the form of an intra-muscular injection. This is an injection into the muscle of the buttock. It is rarely used now in the UK except for resistant types of tuberculosis. Once again, your doctor will want to take blood samples to see how your liver and kidneys are coping with the drug. People who have had*

*liver or kidney problems in the past are more at risk of developing serious side effects. Other side effects include numbness and tingling in and around your mouth, and long term usage can cause permanent damage to your hearing. It is really important to tell your doctor if you experience ringing in the ears (tinnitus).*

If you do not respond to isoniazid and rifampicin, you are considered to have multidrug-resistant tuberculosis. This is more serious as it may take longer to treat. It is treated with what are called 'second-line' drugs. The side effects with these agents may be more severe than with the drugs listed above. We will avoid talking about these drugs as the subject is so highly specialised, and your doctor is really the one to ask about what sort of side effects you may get. MDR TB is still relatively uncommon in the UK.

Medicine for treating TB is relatively safe. Sometimes the drugs cause side effects. Some are minor and can be lived with. Others can be more serious. If you are having any side effects, tell your TB specialist or nurse about them. The side effects listed below are, according to the Centers for Disease Prevention and Control's *Questions and Answers about TB*<sup>2</sup> booklet, more serious and you should contact your TB specialist or nurse immediately if you experience them.

- *No appetite.*
- *Nausea.*
- *Vomiting.*
- *Fever for 3 days or more.*
- *Abdominal pain.*
- *Tingling in the fingers or toes.*
- *Skin rash.*
- *Easy bruising or bleeding.*

- *Aching joints.*
- *Dizziness.*
- *Tingling or numbness around the mouth.*
- *Blurred or altered vision.*
- *ringing in the ears.*
- *Hearing loss.*

## **HOW LONG WILL I BE ON TREATMENT?**

When people have healthy immune systems and a drug sensitive TB, the treatment will usually last for 6 to 9 months. However, it can be longer; possibly as long as two years.<sup>3</sup> For people who are immuno-compromised, the treatment may be longer (my treatment lasted 3 years). Clearly, a healthy immune system assists in combating the disease.

## **TAKING YOUR MEDICATION**

If you have TB disease and start treatment, you are likely to feel better in a couple of weeks.<sup>4</sup> It is also likely that you will be non-infectious after this period of time. Your doctor will be able to tell you whether you are infectious or not from your sputum samples.

Even if you feel better, and the doctor says you are not infectious, this does not mean that you are cured. The TB bacterium takes a long time to kill because it replicates so slowly. It may be hiding somewhere: the doctor can tell if it is from the sputum culture samples.

All of the bacteria must be killed, or the TB disease may come back. Some people make the mistake of stopping taking their pills when they feel better.<sup>5</sup>

## **TREATMENT FAILURE**

Rosy Weston, a senior GUM / HIV pharmacist at St Mary's Hospital,

has had experience of these problems and gives the main reasons why some patients do not take their medication properly:

“There are two main reasons why individuals may not adhere to medication. Firstly, there is ‘intentional non-compliance’. This occurs when the individual makes a decision to miss a dose or change the way the medication is taken. An example of this is when you know that a certain drug makes you feel really sick just after taking the medicine, so you decide - or take advice from someone - not to take the drug.

“Another example which is very common involves taking a course of antibiotics. Although you have been recommended to take the drugs for 10 days, for example, you feel so well after 5 days that you stop.

“Then there is ‘unintentional non-compliance’. This occurs simply when an individual is unaware that they may be taking the drugs incorrectly e.g. the wrong dose or simply forgetting to take a dose.”

There is an element of truth in Francis Bacon’s comment that: “*The remedy is worse than the disease.*”<sup>6</sup> Like many forms of chemotherapy, TB treatment can have unpleasant side effects that can be very hard to cope with. The second-line drugs used in the treatment of multidrug-resistant tuberculosis are particularly challenging. In some ways, the side effects can feel worse than the disease itself, and avoiding unpleasant side effects may be the object of stopping medication. It is extremely important that you continue with the medication. If you are having problems with side effects, talk to your TB specialist or pharmacist about them to ensure that you are doing all you can to overcome them.

Before you start taking your TB medication you may consider asking your doctor, nurse or pharmacist the following questions:

- *What are the most common side effects I should look for?*

- *How soon can they appear and how long do they last?*
- *What can I do to reduce the effects?*
- *Are there any other drugs I can take to help?*
- *Are there any information leaflets I should read?*

Poor compliance is the main reason for relapse into TB disease.<sup>7</sup> Your doctor will test your blood and urine, make random pill counts and check prescriptions. He will know if you are not taking your pills!

In extreme circumstances, you should be aware that if you fail to comply with treatment and pose a risk to others, you could be incarcerated in the interests of public health. This comes under the definition of ‘reasonable force’ to ensure detention. A court order could be taken out against you to enable this. As far as Dr Jane Leese, a senior medical officer at the Department of Health, is aware, this action “hasn’t been tested in a court of law”. I wouldn’t recommend allowing it to be tested. You can be responsible for your own health and the health of others, and at the same time maintain your civil liberties.

## **DIRECTLY OBSERVED THERAPY [DOT]**

The good news is that, if detected and treated properly under medical supervision, most patients with TB recover. Failure to respond to treatment - usually around 5 % - occurs in those people who are poorly compliant.<sup>8</sup> There are ways of ensuring compliance; unfortunately, treatment takes a while, and discipline is an essential ingredient in defeating the disease.

The World Health Organisation has said that the most cost effective way of treating and preventing tuberculosis is the ‘Directly Observed Therapy’ programme or DOT for short.

During Directly Observed Therapy (DOT), a health care worker

or other monitor ensures that TB medication is administered effectively.<sup>9</sup>

Some health authorities have a team of DOT 'monitors' who are not necessarily trained to a high nursing grade - but are just as effective at the job. DOT can sometimes feel intrusive, but has major benefits. Not only do you always take your pills correctly, but you can build a relationship with the monitor. You are able to talk to them about side effects as they occur, any fears you may have about the disease, and all sorts of other more mundane problems. You feel supported and know you are being treated correctly.

It is hard to take what sometimes is a huge amount of medication and suffer the side effects. A regular day-to-day qualified friend can really make a difference.

## DIARY: TREATMENT

*Having left hospital I had to face the months at home, not being able to see most of my friends and I found this hard. I was given TB medication as a precautionary measure: these were the second-line TB drugs which sometimes have harsh side effects. Generally, this is unusual and not everyone will go through such a bad experience. My doctors were being extra cautious because they knew a multidrug-resistant TB strain was in circulation at that time.*

**FRIDAY 4TH AUGUST 1995** This morning the district nurse came to see me. The doctors have put me on a programme called Directly Observed Therapy or DOT for short. This means that I have to be watched taking my medication twice a day. I feel a bit like a naughty boy. Firstly, locked up in my room and told to stay there until I am allowed to come out; and now

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'nana' says that good boys must take their medicine. I'm in a foul mood because I would like to go out with my friends. We are going to have a big party when this is over, I can tell you that for sure.

**THURSDAY 10TH AUGUST 1995** I cried again last night. I feel so confused. I know it's the medication and there is a distinct feeling that I am going to have to do battle. Crying is something that I have never been very good at. However, in the last few weeks I've found it has relieved some of the tension that I've felt.

I am trying to focus on the fact that it is the medication that is making me feel this way. It is strong and makes me feel woozy, but I know that I have to take it. I must try to see the side effects in a positive light. When I have them, at least I know the medication is working.

I spoke on the phone to one of the other employees from work. He told me that because he had been in contact with me, he had been told that he couldn't return to work until he had been cleared of the disease. I began to feel scared again - and guilty. I know this wasn't my fault, but it's hard to come to terms with. He was fine with me though. Sometimes I feel there is a sense that we are all in this together, helping each other. Strange. I feel supported and lonely at the same time. We talked about having that party. It made me laugh and I felt dizzy again.

**FRIDAY 11TH AUGUST 1995** I still haven't got used to the district nurse coming so early to watch me take my medication. I have never been an early riser. She arrived about 9.30am. Her name is Valerie; I quite like her because she talks and has a cup of tea with me. I want to talk to her about the side effects I'm having, but I don't quite know how. The drugs seem

to affect my way of thinking, as well as the more physical side effects. I'm not sure if she wants to talk about thought processes at 9.30 in the morning. Maybe another day.

I'm still sore from the streptomycin injections that I've had over the past four days. We had been alternating where they went: right buttock one day, left the next. They are deep injections and I've never been very good with needles. The fact still remains that I don't know which way to sit because my bottom is so sore. My legs feel like lead and it's becoming difficult to move about. Streptomycin is the one I hate most.

After Valerie left, my friend took me to the hospital so that I could hand in the samples of various bodily fluids I had lovingly created that morning. They were monitoring my progress. The urine sample was easy; the sputum was a bit more difficult. I didn't have a cough and it was difficult to bring anything up. A few slaps on the back seemed to get the ball rolling. I like the phrase 'cough in a pot'. It reminds me of 'cat in the hat!'

I hoped I'd coughed up enough as I walked upstairs to the clinic. The nurses asked me how I was feeling when I got there. I told them all right, barring the side effects of the medication. They took some blood and that was it. Time to go. My legs feel so stiff. I think it might be because the streptomycin is put into the muscle, but I'm not sure.

I am amazed that I got home without collapsing. I can only assume that this was because of the injections and the other drugs I'm taking. I should really ask. I need to know these things.

When I got home I lay down on my bed. I put on a healing tape. My partner absolutely hates it! He says it's New Age crap. Whatever he may think, it sort of half worked. The digital clock flicked over. It was 5.30 in the afternoon. I lay back into the four pillows I had stacked up and poured on some lavender oil. My

back feels so knotted up, and all I can do is toss and turn restlessly. I started to relax after a while and my legs began to feel slightly better.

**SATURDAY 12TH AUGUST 1995** The doorbell rang about 10 am. It was the district nurse again. I had slept quite well that night. I must have been tired, and when I got up to answer the door I was surprised to see how late it was. I took my pills and had my injection. I was too tired to talk. I wanted to ask about side effects, but I didn't feel up to it.

Later, I sat there alone. The effects of the tablets had really taken their hold by now. I moved off the sofa onto the floor and crawled to my bedroom and onto the bed. Once again the strains from my New Age tape rang out, and I was flinging lavender oil around the room. It mixed with the smell of my burning cigarette which I was taking a deep draw from. Stab. A pain struck in my chest. It got worse. My throat felt dry, I started to cough. I knew something wasn't right. It wasn't just the side effects I was feeling. I thought back to the samples I had given to the hospital: will they want to isolate me again if they find out how I am starting to feel? My head feels like a merry-go-round.

I am so frightened every time there is a knock on the door or if the telephone rings. Even if a police car comes down the street, I wonder if they are coming for me. It is the deranging effects of this medication: I know it alters my thoughts, but it still feels real. I feel like I am living with the daily prospect of being locked up. Like some sort of fugitive. The nearest thing to this that I have ever been through is being sent to my room as a child, only this isn't a child's game. It is all far too adult. I wonder if the association I make with being a naughty boy is the reason for the guilt feelings.

I lit another cigarette and felt that pain in my chest again. It was quite constant, and I wondered if this was a side effect or the

thing they were trying to prevent. I lay there for what must have been hours. Then the doorbell; it was about 6pm. It was the district nurse. She came in, watched me take my pills, and left.

I was alone again. The pain was still there. I hadn't told the nurse about it. I hoped it would go away. I wanted it to go away. I didn't have a temperature, but the pain was familiar. By 8.30pm I was very worried. The pain hadn't gone and now I definitely had a temperature. I wasn't coughing anything up. Perhaps I was overreacting.

I have read in my *Complete Home Medical Encyclopaedia of Symptoms* by Dr Sigmund Stephen Miller that the disease TB can "occur insidiously with a slow loss of weight and gradual insidious fatigue and then explode into what is often chillingly called 'galloping consumption'. In a short space of time the patient becomes emaciated, his skin turns greyish, he develops a cough with bloody sputum, and almost every night drenches his bed with sweat. Before the advent of new drugs, 'galloping consumption' would kill in a matter of weeks."

I could almost hear the voice of Vincent Price in my head as I read the description. I even tried reading the section out loud in his voice. It wasn't long before I fell about in fits of laughter. Perhaps I am going mad. Then the fear again. I was terrified 'it' was going to get me. Was I going to be chucking up gallons of frothy blood, and then explode into 'galloping consumption' just like the book said?

Up until now I hadn't really suffered from any actual symptoms of the disease as described by the book. My main problems were the psychological ones of dealing with what might happen to me and the effects of the medication. They had progressed from bad to worse. Things are so uncertain. I will try not to be frightened tonight as I go to bed. Perhaps by morning it will have passed.

**SUNDAY 13TH AUGUST 1995** The noise of

the doorbell blended into my dreaming. I woke with a start when, for a second time, the district nurse pushed the button: longer this time. I struggled out of bed. I wasn't feeling too good this morning. I had only managed to get about four hours' sleep: it wasn't a constant sleep, but it was all I could grab in between the hours of worry.

The district nurse commented on how I looked. I told her that I never looked my best when I woke up. (And judging by the look of her she probably didn't either, I thought.) I wasn't in the mood this morning. A handful of pills and an injection later and she was gone.

I smoked the last cigarette in the packet. I am smoking more than I usually do these days. About forty a day. Still, this is better than when I was in the isolation room, when I was smoking about sixty a day. I had put some of the pain I felt in my chest down to my excessive smoking. Today my chest is feeling better; I'm not coughing and I haven't got a temperature. This is something to be glad about. I don't think they will isolate me again if I don't have any of these symptoms.

I realised that my appointment to find out my sputum results was scheduled for about 5pm the next day. Originally it was going to be at 2.30pm, but they changed their minds. Was this in anticipation of me being infectious, and them not wanting me to sit in the waiting room with lots of other people? Were they ready to admit me the next day? Was this my last day of freedom? I am feeling totally paranoid.

I must try to keep things in perspective underneath the weight of the medication. I must focus on the day, or even the moment, and just to try and keep my sanity. I asked myself: "Was I infected or not? Was I a danger to other people?" These are difficult questions to answer, especially when so many of the factors involved are unknown.

I feel as though I am swinging between feeling quite well and

feeling ill. I can only assume it's the medication. My legs still feel like lead; sometimes I wake up and feel paralysed for a few minutes. It is not a feeling I enjoy. I used to sleep well. Now it's a chore to get through the night. Even my tape and lavender oil don't work - things I used to swear by. Perhaps it is all New Age crap after all as my friends tell me.

The fear of dying comes and goes. The thought that I may be dead in a few months and die alone in some clinical isolation unit away from those I love fills me with such fear. Once again I fantasise. If I was dead, at least I wouldn't be frightened any more.

I went to bed at about 10pm which is quite early for me - something didn't feel right. When I woke up, I judged it to be about 4.30am. I thought I had been asleep for a while. To my surprise I looked at the clock and it was 11.30pm.

The pain in my chest had got worse and I was having difficulty stopping myself from coughing. I took another painkiller and then took my temperature. I knew I had one; I just didn't know how high.

After a minute or so I took the thermometer out of my mouth and twiddled it around to read it. 38.5 °c. I knew what I had to do and telephoned the hospital. I couldn't wait for my appointment at 5pm to get my result. My body was already telling me what it would be.

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## TB TIPS: MEDICATION

### ■ STORING YOUR MEDICATION

There are ways of storing your medication other than just leaving them in their bottles in a carrier bag. Using containers such as a "dosett" box or "medimax" to store a day's supply of drugs allows you to see if you have taken the drugs.

- If you want to store or keep your medicines in a container or pack other than the one the pharmacist has supplied, always check it is okay to use boxes such as those mentioned above. Some drugs need to be stored away separately, otherwise they may lose their potency. If you do take your medicines out of the pharmacy container and put them with other pills, it is best that you only do this with one day's supply.
- If you can't get the boxes, try sputum sample containers. Write the days of the week on them, indicating whether this is your morning or evening dose. They can easily be carried around in a handbag or pocket. If you don't want them to rattle, just stuff some cotton wool in the pot with the pills.

## ■ **TAKING YOUR MEDICATION**

- Taking large quantities of pills may seem physically impossible to some. My advice is to set aside some time to take them. Bolting them down may result in you feeling nauseated, and you may even vomit. If you do have a problem with nausea, tell your TB specialist; it may be possible to help you with this. Obviously, if you are vomiting you won't absorb any drug, and the TB may come back.
- Some people find it difficult to remember to take their medication. Try putting your medicine in a prominent place, for example by your tea or coffee in the morning. You might also like to try using an alarm: a bleeping watch or a computer may help you remember. Encourage a friend or family member to help to remind you to take your medication.
  - The most important thing is forward planning. Always carry an extra dose of medication with you. Know when your pre-

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scription is due to run out and how to get more tablets. If you are going to travel, never keep all of your drugs in a suitcase in a baggage hold: always have some 'extra doses' on your person.

- I would constantly affirm to myself that the pills were doing me good and, that if I kept taking them regularly, one day I wouldn't need to anymore. Believe me, when that day comes you will be glad of your self-discipline.
- It may feel like your body really isn't going to cope with the pills you are taking. I found taking them with a yoghurt and a glass of water helped them to go down. It also seemed to make the pills a little more gentle on the stomach.
- If you are a regular (or heavy) alcohol drinker, speak to your doctor about it. It is unlikely to be compatible with the medication you are taking. You may be able to get extra help.
- You may find you develop thrush in your mouth and/or throat. It is a common affliction for people who are immuno-compromised, or who are taking large amounts of antibiotics for a long period of time.
- You may have thought about trying homeopathic or other alternative therapies on their own. Forget it! Although these therapies are a useful addition to routine medication, they will not cure you of TB.

## ■ CHILDREN WITH TB POSE SPECIAL PROBLEMS

Try not to get upset: taking TB medication becomes very routine, and it could be made worse if you and your child end up

fighting over it every day. I would suggest resorting to plain old bribery: try using sweets after they've had their pills, but don't mix the two. You might promise them a big surprise at the end of their treatment. Discuss any problems, such as point blank refusal, with your doctor. Some TB drugs come in syrup form. *Keep medication out of children's reach.*

**■ DEALING WITH SIDE EFFECTS**

I am not going to lie to you. Some of the side effects are really horrible. Especially the older and second-line treatments. I personally needed counselling to get me through. There were many times I sat there on the floor in tears surrounded by bottles of pills.

- In my experience doctors are very good at treating conditions such as TB, though they don't always grasp how side effects make people feel. If your doctor seems unsympathetic, ask to see a counsellor or a clinical psychologist. Sometimes they know other ways of dealing with side effects.
- If you are not already on the Directly Observed Therapy programme, ask to be put on it. I eventually found the programme provided much-needed emotional support.