Overcoming Tuberculosis

A Handbook for Patients

Paul Thorn • The Tuberculosis Survival Project

Stop TB Partnership

OVERCOMING TUBERCULOSIS:
A Handbook For Patients

Paul Thorn

THE TUBERCULOSIS SURVIVAL PROJECT

In memory of John Campbell

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Introduction

Welcome to Overcoming tuberculosis: a handbook for patients. The information contained in this booklet is applicable to anyone who has tuberculosis (TB) or multidrug-resistant TB (MDR-TB), wherever they live in the world. This handbook is written to help you understand what TB/MDR-TB is; how you can get the disease; how it is diagnosed; how it is treated and cured. Yes, that's the good news: TB/MDR-TB is curable! There is no big secret to being cured of TB/MDR-TB. Both are curable when the patient takes all of the TB/MDR-TB medicines as their TB doctor or nurse tells them to. You too can be cured, like millions of other people around the world and again lead a healthy and productive life.

So why the need for this booklet when it all sounds so easy? The fact is that some people do find treatment of TB/MDR-TB difficult. The medicines can sometimes cause unpleasant side-effects, and the treatment takes a long time. For some patients, TB treatment may seem like an impossible mountain to climb. Let me assure you, it is not. This booklet will help you to understand TB/MDR-TB and why taking your medicine is so important. It also includes tips, called "TB tips", written by people who have actually had TB/MDR-TB. They are meant to offer more practical advice and appear at the end of each chapter. At the end of this book you will find a treatment chart to help you monitor your own TB/MDR-TB treatment progress.

So, what qualifies me to write about surviving TB/MDR-TB? My name is Paul (Mayho) Thorn. I am a former health-care worker and wrote a book called The tuberculosis survival handbook that was published in 1999. In 2006 a revised second edition was also published. I have been active in the fight against TB/MDR-TB for over a decade now. I am also a survivor of the disease...

Here is my story briefly. In 1990 I was diagnosed positive with the human immunodeficiency virus (HIV). In 1995 I was in hospital with an HIV-related infection. It was while I was a patient that I became infected with MDR-TB by another patient who was also on the same hospital ward. I lost a lot of weight, was drenched in night sweats and had a terrible cough that sometimes had blood in it. I was isolated in a room alone. The most difficult aspect of having MDR-TB was that I found the whole experience very frightening and lonely. It seemed that no one understood what I was going through. It also felt like there was no one who could help, other than to give me hundreds of tablets to take. I was very sick and even thought that I was going to die. But I didn't.

The reason I am here today is that I took all of the medicines that were given to me as the TB doctor and nurse told me to. Even when I was so sick, with treatment there was always hope. Today I lead a very productive and enjoyable life again and am cured of MDR-TB. The key to my own survival was a good understanding of TB/MDR-TB and perseverance with TB treatment. This booklet, I hope, will go some way to improving your own understanding of what is happening to you and guide you through your very own TB treatment journey. Finally, I promise those of you with TB/MDR-TB: you are not alone. There are thousands of others just like you out there, all around the world. Most of them will be cured because they followed some simple rules. This book will show you too.

To find out more about surviving TB/MDR-TB, log onto the TB Survival Project web site at www.tbsurvivalproject.org.

The Tuberculosis Survival Project is proud to be a member of the Lilly MDR-TB Partnership.

Paul Thorn, London, England, 2007

Chapter One. Understanding TB

This chapter will provide you with a foundation of knowledge that needs to be understood before reading the next few chapters. I have tried to keep things as simple as possible. Please note also, from now on, that when I talk about "TB" I am also talking about "MDR-TB", unless I specifically mention otherwise.

What Is Tuberculosis (TB)?

Tuberculosis (TB) is a contagious disease caused by a germ called "Mycobacterium tuberculosis" or "M. tuberculosis". Germs or "bacteria" are tiny living organisms that reproduce by dividing, and can be shaped like a sphere, rod or spiral. They are present virtually everywhere. Some of them are harmless – others are very dangerous. The dictionary definition of a mycobacterium is: "a Gram-positive rod like genus of aerobic bacteria, some species of which are harmful to man". For many people, myself included, this sort of scientific language isn't very accessible.

With further reading, I have found many very good definitions of tuberculosis. I find the American Lung Association's most understandable. That organization defines TB as an infectious disease that usually attacks the lungs but can attack almost any part of the body. It is spread from person to person through the air. When people have TB in their lungs it is called pulmonary tuberculosis. It is transmitted when an infectious person coughs, laughs, sneezes, sings or even talks, as the germs that cause TB may be spread from their lungs into the air. If another person nearby breathes in the germs, there is a chance that they shall be infected. TB germs do not survive long in the air and if someone happens to be in the same room where a TB patient was, but now the room is empty, then there is very little chance of infection. When TB isn't in the lungs it is called "extrapulmonary" TB. If a person has TB elsewhere in the body other than in the lungs or throat, they are not infectious, because the germs need to be breathed out. However, it is still very important that any form of TB is treated with TB medicines.

Left untreated, TB in the lungs or anywhere

else in the body can kill. According to the World Health Organization, 1.6 million people died of tuberculosis in 2005. The disease is a bigger killer than malaria and HIV/AIDS combined and takes the lives of more women each year than all combined causes of maternal mortality. The good news is that tuberculosis is a disease that we know a lot about and can cure ... if it is treated properly and the patient takes all of the TB medicines.

What is the difference between "latent" TB infection and "active" TB disease?
There is a difference being merely latently infected with TB and having active TB disease. For some this is a difficult concept to understand; I shall try to explain it as simply as possibly. "Latent" TB infection and "active" TB disease are different.

Latent TB infection
Think of latent meaning "dormant" or "sleeping". TB germs can live in your body without making you ill. This is called latent TB infection, which is non-infectious to others. Indeed this is very common and in most cases it is nothing to worry about, as the patient probably won't ever become sick. According to the World Health Organization (WHO), one in three people of the world's population already has latent TB infection. That simply means that they have breathed in the TB germ at some point in their lives, but the body's natural defences make the germ "sleep" effectively, making it inactive.

However, sometimes the TB germs "wake up" and break away from this trap set by the body's natural defences. When this happens the "actual" TB disease can develop. Some doctors may think it wise to give a patient who is found to have latent TB infection medicines to make sure the patient doesn't become ill as a precautionary measure. It is very routine, especially for people who are HIV-positive.

What are the symptoms of "active" TB disease?
As I have explained, if you have latent TB infection then you will not feel ill, have symptoms and won't be infectious. But if you develop active TB disease then you may feel weak and tired. You might start to lose weight. If you have active TB disease you may also lose your appetite. You might develop a fever, and possibly night sweats.

When TB is in your lungs (pulmonary TB) you may get any combination of the symptoms mentioned above, but also accompanied by a cough. You may have chest pain and might be coughing up some blood or blood-stained phlegm (sputum). 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, and potentially your family, especially young children, in danger.

The symptoms of TB 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, and you are HIV-positive. If you are taking TB medication and these symptoms develop you should tell your TB doctor or nurse. The TB medicines you are taking may not be working properly, and they may need to change them.

Who can get TB?
Absolutely anyone can be latently infected

with TB. But some groups of people are at a higher risk of developing active TB disease. These include:

- people with poor nutrition;
- people who smoke;
- people who are homeless;
- people who come from countries where there is a high incidence of TB;
- people who work in mines;
- people in nursing homes;
- people who are prisoners;
- people with alcohol dependency;
- people who are intravenous drug-users;
- people with medical conditions such as diabetes or certain cancers;
- people living with HIV or AIDS;
- people living in poor and overcrowded living conditions.

What is multidrug-resistant tuberculosis (MDR-TB)?

You may have heard of multidrug-resistant tuberculosis (MDR-TB), but what is it? MDR-TB is just like TB as it is explained above, it has the same symptoms and you get it in the same way as TB. It is no more infectious than common TB. Indeed, it very similar in every way except that the tablets usually used to treat common TB don't work as well and different TB tablets and injections need to be used for two years. MDR-TB is very serious as it is harder to cure.

Let me try to explain. The germs that cause TB, like you and me, are living things. And like all living things they don't want to be killed. Sometimes TB germs can start to understand how the medicines usually used against them work. This happens when someone with TB misses times when they should take tablets asthe TB doctor or nurse told them to. When someone with TB misses their tablets it creates gaps when the TB germs have extra time to understand and learn how the tablets work. When TB germs know how the medicines work it can avoid being killed by them, so they stay alive and continue to reproduce making a person with TB sick again. When the TB germs understand how the medicines work and stop working as well as they usually should, then this is called multidrug-resistant TB or MDR-TB.

MDR-TB happens in one of two ways. The first is that you can come into contact with someone who already has MDR-TB and is infectious and you breathe in the already drug-resistant TB germs. The second is that someone may start off with common TB, but does not take all of their TB medicines properly. Then the germ "learns" how the drugs work and the TB "changes" from being standard or common TB and becomes MDR-TB.

If you have MDR-TB and you still continue to not take your medication properly, the TB germs learn even more until the TB medicines won't work very well, if at all. When this happens it is very serious and called extensively drug-resistant TB or XDR-TB.

What is extensively drug-resistant tuberculosis (XDR-TB)?

Extensively drug-resistant TB (XDR-TB) is even more serious than MDR-TB. I described a process above whereby the TB germ can learn how the TB medicine usually used against it works. When this happens the TB germ becomes resistant to treatment. When the TB germ recognizes the main preferred medicine used to cure the disease this is called

MDR-TB. If the patient with MDR-TB continues to not take their TB medication as their TB doctor or nurse tells them to, then there is a chance that the severity of the resistance shall increase. When MDR-TB becomes even more resistant to the special medicine, called "second-line" TB treatment, then the options for cure start to become more limited. This is because there is a lack of drugs that can cure this form of TB. This is called XDR-TB.

It is not known how common XDR-TB is, only to say that it is rare. However, the increasing identification of XDR-TB in some parts of the world is very worrying. MDR-TB and XDR-TB are both transmitted in the same way as common TB. It means that anyone can be infected and they may go on to develop active disease. If someone is found to have XDR-TB, it is quite possible that they shall be isolated at home or in hospital to prevent passing on the drug-resistant germ to anyone else (See Chapter four on Isolation).

The best way to avoid any chance of MDR-TB, or XDR-TB developing is to ensure that you take your TB tablets as your TB doctor or nurse tells you to and only stop when they say you can. Drug-resistance can be prevented. It is best not to let it happen in the first place. XDR-TB can be extremely difficult or in some cases virtually impossible to cure.

Tuberculosis and the HIV virus

In some parts of the world there are many people living with HIV. When someone is HIV-positive the chances that they may develop active TB disease increases. Large numbers of the world's population, as mentioned earlier, are latently infected with TB. As I have made clear, it's very common and doesn't mean that a person is infectious and can pass the disease onto others. In other words, although the TB germs are present in the body, the disease does not develop, remaining asleep (like a volcano that is dormant and probably won't ever erupt, so to speak). This is because when our body is healthy, its defence mechanism stops the TB germs from multiplying. However, if for any reason the body's defence mechanism is weakened (for example by having HIV), the germs are no longer controlled and can wake up, then the latently infected person can become sick with active TB disease.

Chapter Two. Diagnosing TB

This chapter explains how TB is diagnosed. MDR-TB and XDR-TB are diagnosed in the same way. To be able to explain diagnosing TB we need to understand something of the history of the disease and the medical breakthroughs that meant we could see the TB germ for the first time and the tests to detect TB that were discovered afterwards.

Tuberculosis: A Very Brief History

The story of TB is a very old one. It may surprise many to know that the disease has been about since humans have walked the earth. Indeed, evidence of TB has been found in the fossilized bones of cave-bears and in Egyptian mummies. Hippocrates, the famous ancient Greek doctor, called the disease "phthisis", a term formerly applied to many other wasting diseases and usually connected with the lungs. He probably called it this for the same reason that it was called "consumption" many centuries later. The disease, as we shall find out later, occasionally causes dramatic weight loss and probably accounts for this name, as it can appear that the person with TB is being "consumed" by the disease.

Tuberculosis can affect almost any part of the body, not just the lungs. Historically, one of the most common occurrences was the germ attacking the lymph glands, often in the neck. This was given the name "scrofula", but was more commonly called the "King's Evil", because of the widely held belief that the touch of a royal hand would cure the afflicted person. Of course this is not true. The only way to cure TB (and MDR-TB) is to take the right tablets given to you by your TB doctor or nurse.

In 1720 the English doctor Benjamin Marten published A new theory of consumption. He described the disease as being caused by "wonderfully minute living creatures". It was a good guess. He wasn't wrong, but the germs he imagined, but could not see, were not officially discovered until over 160 years later.

In 1882 the German scientist Dr Robert Koch announced the discovery of a technique that enabled him to see the TB germ under the microscope for the first time. He achieved this by a method that involved using a special type of dye to colour the TB germ so that they show up easier for examination. Most germs once stained with dye and washed with a special acid solution lose the colour of the dye. But the germ that causes TB and MDR-TB does not lose the colour of the dye when washed because it has a special waxy outer coating. TB doctors and nurses call the TB germ when they can't wash off the dye, "acid fast". Dr. Robert Koch's discovery was an important one as it meant the battle against TB could really begin.

Another important discovery in the more recent 20th century was by two French doctors, Calmette and Guérin. They found a non-dangerous and "tamed" version of the TB germ. It created the basis for a vaccine against TB called BCG ("Bacille Calmette–Guérin"). It is still in widespread use today. You may have had this vaccination. Some people can tell if they have had the BCG because on their upper left arm there shall be a scar. However, having the BCG vaccine only offers some protection, especially in very young children, and is not 100% successful in stopping TB. It is important even if you have had a BCG vaccination that if you have the symptoms of TB that you are tested to see if have TB.

During the Second World War the first drugs against TB were developed. The next few years saw even more new drugs being found. By the time of the 1970s many people thought that the battle against TB had been won. Unfortunately they were wrong.

Diagnosing latent TB infection

Latent or dormant TB infection can be diagnosed usually by one of two special skin tests. (Although sometimes a blood test is used, but this is not as common as the more traditional skin tests.)

The most commonly used skin tests are called the Heaf test and the Mantoux test. They both work in virtually the same way. The Heaf test uses a tamed and safe substance called "tuberculin" based on a very close relative of the TB germ, which is smeared on to the skin. An instrument called a Heaf gun makes small puncture sites where the tuberculin substance has been spread. The test is usually carried out on the inside of the forearm. It doesn't really hurt and doesn't scar. After about seven days a TB doctor or nurse checks the site where the test was carried out to see if you have reacted to the test.

The Mantoux test is very similar, except that a single injection is usually given 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 see if you have reacted to the test.

A positive skin test result shows that you have reacted to the tuberculin. It does not necessarily mean that you are ever going to become infectious or have active TB disease. However, your TB doctor may decide to put you on TB tablets to make sure you don't go on to develop active TB disease.

A negative result would suggest that, at that time the test was done, you are not infected with TB. This is not conclusive. The test may be falsely negative in a person who has been

recently infected. It usually takes from 2 to 10 weeks after you have been exposed to a person with active TB disease for the skin test to show a positive result. In addition, if your body's defences aren't working properly (such as in the case of HIV infection), this can also produce a negative skin test result.

Diagnosing active TB disease

Active TB disease is diagnosed in a number of different ways. The doctor may exercise judgement based on your symptoms (as previously discussed). The doctor may feel safe enough making this guess because you come from somewhere where there is a lot of TB, or you are latently infected and may be at risk of developing active TB disease.

Chest X-rays are also used to assist in the diagnosis of active TB disease. Areas in the lungs affected by TB appear as white spots that may be tiny holes (cavities) caused by the TB germ; there may also be some abnormal shadowing.

The doctor may test a sample of phlegm (sputum) from you using the staining technique I explained earlier. (By first staining the sputum sample with coloured dye and then trying to wash it off with a special acid solution) to see if any germs can be seen when looked at through a microscope. This method provides the basis for two tests. The first (and quickest) is called a smear test. The sample of sputum is looked at under a microscope to see if any TB germs show up after staining and washing. If you are "sputum smear positive", TB germs 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 germs that show when stained with dye and washed with the special acid solution. The more "+" you have, the more infectious you are likely to be.

If you have active TB disease your TB doctor or nurse will want lots of sputum from you. Indeed, they get very exited over it! Your TB doctor or nurse can then monitor whether the TB tablets are working by looking for TB germs in the sputum samples given by you throughout your treatment. You will find that your test results get better as the tablets kill the TB germs. Eventually, the grading of the 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 doctor or nurse will want to carry out a second test called a culture test. This means they try to grow TB germs in laboratory conditions over a period of time; this usually takes about 8–12 weeks.

If the culture test is positive it means that TB germs are still present and treatment needs to continue. If the result is negative, your TB specialist will want to carry out further cultures before you can be classified as cured.

What is contact tracing?

Your doctors may need to test other people you have been in contact with to see if they have also been infected. You may be asked for a list of these people. Usually, this will be confined to close contacts such as your

family, people that you live with or those you have regular contact with, especially young children even if they have been vaccinated. This might be embarrassing, but it is important to make sure that no one else you have been in contact with has caught TB from you. Indeed, it may be someone else close to you who passed TB to you. They will also need to be treated.

TB tips: general

- TB is curable – If you feel you have been near to someone with TB or MDR-TB, don't panic!

- If you are in contact with someone 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, e.g. a 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) is 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 good trustworthy 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% of people go on to develop active TB disease. However, if you are HIV-positive, 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. They are less likely to talk in such technical jargon.

Chapter Three. How Is TB Treated?

If you are diagnosed with active TB disease your doctor will want to put you on several different TB tablets to cure you. There are a variety of tablets that are used in combination with each other. If you have common TB it is easier to treat than MDR-TB or XDR-TB.

Side-effects

All tablets, whatever they are for, might cause side-effects. TB tablets are no different but are considered relatively safe. There are quite a few TB tablets you could be given, and your TB doctor or nurse shall decide what is best for you. I shall not go through each TB tablet individually as side-effects are a very specialist subject. If you are experiencing any side-effects you should always tell your TB doctor or nurse about them. You should never stop taking TB tablets unless as TB doctor or nurse tells you to!

Tell your TB doctor or nurse if you...

- have no appetite;
- feel sick (nausea);
- are being sick (vomiting);
- have a fever for three days or longer;
- have pains in your tummy (abdominal pain);
- have tingling in the fingers or toes;
- develop a rash on your skin;
- start to bruise or bleed easily;
- if your joints ache;
- if you fell dizzy or light-headed;
- if you get tingling or numbness around the mouth;
- if you cannot see properly (blurred or altered vision);
- if you can hear ringing in your ears;
- if you can't hear properly;
- if your pee (urine), tears or sperm turn orange (this isn't dangerous, but can be strange so speak to you TB doctor or nurse for reassurance).

How long will I have to take TB tablets?
People with common TB will be given TB tablets for at least six to nine months. However, it can be longer, two years or more if you have MDR-TB or XDR-TB.

Why must I take all of the TB tablets?
If you have active TB disease and start taking TB tablets like the doctor or nurse tells you to, you are likely to feel better after a couple of weeks. 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 testing your sputum samples in the way that I described previously.

Even if you feel better and the doctor says you are not infectious, this does not mean that you are cured. The TB germ takes a long time to kill and it may be hiding somewhere. All of the TB germs must be killed or it may come back. It is for this reason that it is important to take all of the TB tablets given to you by your TB doctor or nurse. MDR-TB, or XDR-TB will be more difficult and take longer to treat than common TB.

Some patients may stop taking the TB tablets because they feel that TB tablets make them feel really sick, or they take advice from someone who is not a TB doctor or nurse – not to take the tablets. Some people stop taking the tablets because they think they have taken them for long enough already. It may be simply that the patient forgets to take a dose, either all of the time or only some of the time.

I said at the beginning of this book that there is no big secret to being cured of TB. It is simple! All you have to do is to take all of the tablets when the TB doctor or nurse tells you to and only to stop when they say so.

However, as I said earlier, TB tablets can cause side-effects that can be difficult to live with. This is very true of the medicine used to treat MDR-TB and XDR-TB. Some people say that they feel worse on the TB tablets than having 'active' TB disease made them feel! But it is extremely important that you continue with the medication. If you are having problems with side-effects, talk to your TB doctor or nurse 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 TB doctor, or

nurse, the following questions:
a) What are the most common side-effects of taking TB tablets and what should I look for?

b) How soon after taking TB tablets can they appear, and how long do they last?

c) What can I do to reduce the side-effects and/or are there any other drugs I can take to help?

d) Are their any information leaflets on the TB tablets I am taking that I can read?

Not taking your tablets properly is the main reason why active TB disease comes back. Your TB doctor might want to test your blood and pee (urine), and/or randomly count how many TB tablets you have to know if you are taking the TB tablets. The TB doctor will know if you are not taking your pills! If you don't take all of your TB tablets you may be forced to stay in hospital in isolation (in a room on your own) until you do take the medicine and get better. This is so that you don't give TB to anyone else. So it is best to take your TB tablets so that this doesn't happen to you.

What is 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% of cases) occurs in those people who don't take all of the TB tablets. Unfortunately, treatment takes a while, and self-discipline is an essential ingredient in defeating the disease.

WHO has said that the most cost-effective way of treating and preventing tuberculosis is directly-observed-therapy, or DOT for short. DOT means someone trustworthy helps you, such as a TB nurse, to take your TB medicine.

DOT can sometimes feel intrusive, but has major benefits. Not only do you always take your pills correctly, but also you can build a relationship with the person who is helping. You are able to talk to them about any side-effects as they occur, any fears you may have about TB, 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 friend helping you can really make a difference. Speaking from my own personal experience, I truly believe that DOT was the key to me being cured. I encourage you to speak to your TB doctor or nurse if you are not already being helped in this way to take your TB drugs.

(In the back of this booklet you shall find a simple TB treatment chart so that you can follow your own progress.)

TB tips: storing your medication

- There are ways of storing your medication other than just leaving them in their bottles in a plastic 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 phlegm (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.

TB tips: taking your medication and coping with side-effects

- Taking large quantities of tablets may seem physically impossible to some. My advice is to set aside some time to take them. Taking them very quickly may result in you feeling sick, and you may even vomit. If you do have a problem with nausea, tell your TB doctor or nurse. It may be possible to help you with this. Obviously, if you are being sick you won't absorb all of the goodness of the tablets, and the TB may come back.

- Some people find it difficult to remember to take their TB tablets. Try putting your medicine in a prominent place (for example by your drink in the morning). You might also like to try using an alarm: a bleeping watch or a computer may help you remember. Or simply encourage a friend or family member to remind you to take your medication.

- The most important thing with any treatment is forward planning. Always carry an extra dose of TB tablets with you. Know when your tablets shall run out and how to get more when you need to. If you are going to travel, never keep all of your medicine in the same place: always have some 'extra tablets' on your person just in case you lose some of them.

- I would constantly tell myself that the TB tablets were doing me good, even when they made me feel bad, 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.

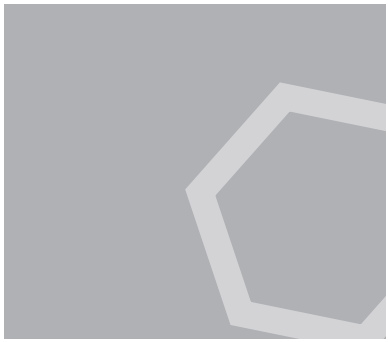
- If you are a regular (or heavy) alcohol drinker, speak to your doctor about it. It is unlikely to be compatible with the medication you are taking. The same applies to people who have had viral hepatitis (jaundice) and drug users. You may be able to get extra help.

- 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.

- In my experience some TB doctors don't always understand how side-effects make people feel. If your TB doctor seems unsympathetic, ask to see a nurse. Sometimes they know other ways of dealing with side-effects.

- If you are not already on DOT ask to be put on it.

- NB. 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 everyday. You might promise your children a big surprise at the end of their treatment. Discuss any problems with a TB nurse or doctor. Some TB drugs come in syrup form that is easier for younger children to swallow. **REMEMBER: ALWAYS KEEP ALL MEDICINE OUT OF THE REACH OF CHILDREN.**



Chapter Four. Isolation.

If you have not been isolated, or are unlikely to be – then you should go straight to Chapter five. If you have already been isolated or are about to be, then this chapter is for you.

Isolation isn't an experience everyone with TB will go through. For those that do, it can be a difficult and emotional time. TB is a disease that is spread from person to person. When someone is found to have active TB disease, they may need to be isolated to receive treatment and to prevent others from becoming infected also.

What is isolation?
Many people who have been through the isolation experience say that it is the hardest part of having TB. Isolation may simply mean that you are to stay away from other people, who may be vulnerable to developing 'active' TB disease, or it may be more formal and you may have to stay in hospital.

You may need to stay for a while in a negative pressure room, or a room with a closed door away from other patients (this is the preferred method of isolation in hospital). The safest form of isolation is the former. A negative pressure room is a room where the air pressure is lower than outside the door. This means that air can only blow in and not out. If your hospital is very modern, you may not even be aware that there is a mechanism creating this lowered air pressure effect. The mechanism is often set in an outer wall.

If your room is a negative pressure room, and the weather is very warm, you will not be able to have a fan. The air pressure in the room would be affected and blow TB germs under the door. The window cannot be opened either, as it will affect the air pressure in the room. The air pressure doesn't feel any lower, and the air doesn't seem "thin" like some people might imagine. In fact, you don't notice it at all. As standard, negative pressure rooms have two doors. Beyond the door to the room itself there is usually another smaller room or chamber, and then a door to the hospital ward.

Isolation does not mean being entirely cut off from people. In many cases, you will be allowed to have visitors. They are often told that by coming into the room they are putting themselves at risk, and are left to make the decision for themselves. Hospital staff might keep a record of their names so that, if any of them become infected, effective contact tracing can be carried out.

Visitors may also be required to have a Heaf test, give phlegm (sputum) samples or have chest X-rays to make sure they have not got TB from you. It is unwise to have pregnant women, children, those with HIV or elderly people come to visit you. If these people really want to visit they should be informed clearly of the risks.

The wearing of masks by people visiting is compulsory to prevent them becoming infected. It is important that they don't take them off. It is also strange to be looked after by people that we can't really see. But it is a necessary precaution to protect them from TB.

How long might I be in isolation?
For some the TB experience is worsened not by the disease itself, but the hardships and loneliness of isolation. Isolation may last a long time. Those who have common TB may only require isolation for two weeks. Others with MDR-TB may require longer, because the TB tablets used to treat the disease work slower than medicine used to cure common TB.

If you are isolated your TB doctor should be able to give you some sort of answer as to the length of your hospital stay. If you have common TB and are good at taking your TB tablets the doctor should be able to give you a good answer. It does help to know how long you are going to be isolated for. If you can see

the days, and count them down, it seems to make the whole experience easier. For those who have Multidrug-resistant TB, the stay in hospital will probably be longer. It might also be harder for your doctor to give you an idea when you may be allowed to leave. Most doctors, particularly in the areas where there is a lot of TB can be quite precise about length of stay.

Isolation and your diet

Spending time away from foods that you normally cook and eat can be hard. Hospital food is well balanced and planned by dieticians. Jane Rowntree, a senior dietician at St Mary's Hospital in London (UK) understands the difficulties: "Some people have food brought in for them. If they do, then it might help to speak to a dietician. The majority of people who have food brought in for them end up with chocolates and that sort of thing which aren't the ideal thing that everybody needs at this time. The thing to do is work out what you want from the hospital menu and what foods you want brought in to you. By eating both, you should get the full spectrum of nutrients you need".

Jane adds: "The balance is important because TB, like many illnesses can cause weight loss and a loss of appetite. Athletes have extremely healthy diets and extremely healthy appetites: they eat lots of high carbohydrate foods like bananas, rice, pastas, but these are not very energy dense. Choice of diet is clearly linked with your appetite, and what you can manage at the time. If you have got a very good appetite, then great! You can eat those sorts of foods, including fruit and vegetables as well. If your appetite is very poor, then obviously you don't want to go for these foods alone because you don't get enough energy from them. You may have to add in some of the things that wouldn't usually be considered particularly healthy; fatty foods for instance".

If your appetite is very poor, it is still possible to obtain the nutrients you need from nutritional supplements. The type of supplements on offer vary, some of them are what are called "complete". That means that you can actually live off them. Others are more specific, and are given depending on the problems that you are experiencing with your food. Some of them are designed just to give carbohydrates, some to increase body mass, and others to provide vitamins and minerals. These have a vital role in providing us with the nutrients we need to aid our recovery. If you are having problems with your food, ask to see a dietician.

Isolation and exercise

Isolation rooms are often very small. However, if you feel well enough you should try to do some exercise. You can do this, even if your room is not big enough for exercise equipment. Ask to see a physiotherapist who will be able to discuss a suitable programme with you. It is helpful to exercise whilst in isolation to keep some muscle tone. If you are not moving around very much this can decline rapidly. Psychologically, it does feel like you are doing something to help yourself, particularly when you feel that you have lost control over your life. This returns a degree of control, just as dietary choices do. When you have TB, there is no better feeling than realising that you are putting on weight. If you are taking your medication, you must be getting better. If you are getting fit as well, this is a bonus.

Isolation emotions

Isolation brings with it its own unique set of coping problems. There is little written about the subject in relation to tuberculosis and the psychological effects. However, there is a study of people placed in isolation following a bone marrow transplant. Isolation is necessary while the transplant is "taking"; during this time the patients are at risk from a variety of infections. This is because their body's defences are artificially suppressed to prevent rejection of the transplant. Note that they are isolated to prevent them from being infected rather than to prevent them infecting others.

In considering a 14–30 day period in isolation, the study found that patients suffered depression, anxiety and disorientation. In addition, some patients complained of difficulty in concentrating. They also experienced odd sleeping patterns, a feeling of loss of control and mood swings.

There are many similarities between both experiences of isolation. The major difference between the two is that bone marrow transplants are planned, and individuals have some time to prepare themselves mentally prior to the procedure. Having TB isn't a planned experience, and the individual is seldom prepared for what follows.

The study further states that: "Patient's concerns are health, family, marital attitudes, financial worries, sexual and social activities, job and daily life, self image as well as the concerns about the disease itself". Patients describe the experience as being in a state of "limbo" or going "stir crazy". The report recommends that patients make structures for themselves in 15-minute blocks of time, requiring them to do their own bathing and formally schedule a time for watching television, making phone calls, exercising and resting. The authors encourage patients to bring in furniture, computers and other items from home that might increase their comfort and help to occupy and structure their days.

Post-isolation emotions

You may have emotional issues to deal with after the isolation period is over. There is no doubt that a period of isolation does affect people, sometimes in very subtle ways. Even crossing the road can be difficult. When you have been sensory deprived in a small space where nothing moves, fast moving cars and buses can be very daunting. My suggestion is initially try to slow down generally, until you find it possible to return to your usual speed. This is particularly important with any potentially hazardous activity: driving, operating machinery, cooking and so on. Take your time and concentrate.

After leaving isolation, you may wake up totally disorientated by your new surroundings, especially on the first few nights at home. You may also find that you dream about being in the isolation room, or have nightmares. This is a natural way for your mind to heal after a bad experience. If you are upset, talk to someone about your difficulties.

If you have an established relationship with a psychologist, psychiatrist or counsellor, then it is likely that you will probably see them again after discharge. Ask to see them if you don't already have regular appointments. Talk about how you are acclimatizing to your new freedom, about sleep patterns, side-effects and any other concerns you may have. One of

the benefits of being on the DOT programme is that you will be building a relationship with whoever has been assigned to your case. It is likely that they will be able to offer you the benefit of their experience with regard to the problems discussed.

Isolation in the community

Isolation in the community means having minimal contact with other people. You should avoid women who are pregnant, children, the elderly or anyone who may be HIV-positive as they may be more susceptible to developing active TB disease. This can be difficult if you rely on support services such as day centres: you may not be able to make use of these. You may also be advised not to use public transport, bars, clubs or restaurants for a while. This can be hard, but it is a necessary precaution. Your doctor will tell you when you can socialize normally with people again.

This form of isolation in the community is only temporary. If you take all the TB tablets like the TB doctor or nurse tells you, then you will eventually be able to lead a normal life again.

TB Tips: coping with isolation

During the course of isolation you may lose an appreciation of the passage of time. Every day feels the same as the one before, and it may be difficult to decide what happened when. It can become very confusing. To combat this:

- Make sure that people close to you know where you are!

- Is there a clock in the room? If not ask if you can have one or get someone to bring one in. Ideally, try to get a clock that doesn't tick. I found that the incessant ticking of the clock eventually drove me "round the bend" – I ended up pulling the thing off the wall and smashing it. It never ticked again, but I didn't know what the time was either!

- Try and establish some sort of routine.

- Open your blinds or curtains when you get up, and close them when you go to bed. Sitting in a darkened room you may eventually confuse day and night.

- If you are well enough, get up and get dressed.

- If you have a telephone, great! Find out if you are responsible for the cost of any calls made. If you don't make any outgoing calls, you can still receive incoming calls and it won't cost you anything.

- If there isn't a telephone in your room, mention it to the staff. It is important to be able to communicate with friends, family and maintain contact with the outside world. The staff should understand and hopefully sort this out. Remember, if you get this organised, there will be a telephone ready for the next occupant of the room.

- If having your own telephone is a real problem, see if there is a pay phone you can use. There should be a pay 'phone trolley on the ward which can be brought to your bed. Obviously, this makes receiving incoming calls problematic. Ask the nurses if they can take any messages for

you, and give the ward number to your friends.

- You may try rearranging the furniture in your room. This helps to personalise it for you and may return a certain sense of control.

- If you have a television in your room, try to watch scheduled programmes e.g. the news. These will act as regular markers, helping to structure your day.

- Most hospitals have someone who comes around selling newspapers and magazines: make sure you are not left out.

- You may feel that you have lost control over many aspects of your life, but you can still exercise some of the rights that we all enjoy. If you are isolated, there will be warning signs on the outer door telling people what to do when they come in. Make one of your own that says: "Please knock before you enter". It is a strange contradiction of isolation: there is very little privacy. There is nothing worse than drying yourself after having had a shower, and a domestic worker decides to clean your room.

- Ask someone to bring some personal effects from home, e.g. pictures or posters. This may help to further personalise things bit and add some familiarity.

- Keep a diary, draw, or do some other activity to make the time pass creatively. It is good to feel you are achieving something.

- Some isolation rooms have a kettle and a fridge so that the occupant can make their own tea. It's not nice to have to ask for a cup of tea every time you want one. If you feel well enough, it gives you a little more independence.

- If you are to be isolated for a while then you are going to need clean clothes. Ask the nurses if they can sort out your washing for you. There are usually facilities for doing this. Make sure you mark your clothes in some way so that they can be identified and returned to you once they have been cleaned.

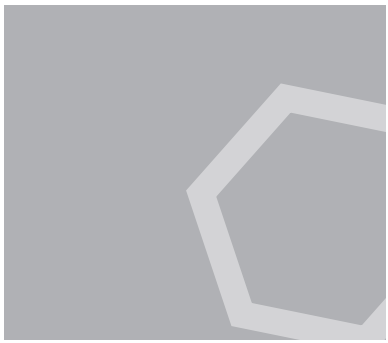
- If you have some space in your room, you may feel like doing a little exercise. Ask if you can see the physiotherapist. He or she may be able to offer some equipment and/or advice. Isolation and weight loss due to TB can lead to muscle wasting. Try to keep some muscle tone.

- Ask to see a psychologist regularly if you are having emotional or mental problems with isolation and possible side-effects of TB medicine. Frustration, resentment and loss of control are common feelings, and they may be able to help you deal with them.

- Remember, you are undergoing treatment. At times it may seem hard, but a relatively short time of discomfort could ensure a complete return to health.

- Try to make an effort with you personal appearance. It is important for your self-esteem.

- Fluorescent lighting gives some people headaches. You should be able to bring in a bedside lamp or other lighting from home.



Chapter Five. Being Cured Of TB

Taking your TB tablets is always the first priority. But there are other things that you can do to maintain your health and prevent relapse. Many people start to think about their lifestyle after a long illness and try to make improvements.

Good lung health

If you have had TB in your lungs, and you smoke, then it is a really good time to give up! Ask your TB doctor or nurse about it, as they may be able to offer some help to stop. Being smoke free is the single biggest thing that you can do to improve your health. Give your lungs a helping hand by stopping smoking as you get better. Indeed many people feel very breathless when they have TB in their lungs and smoking is the last thing that they want to do! Use the experience of having TB to make new improvements to your health.

Eating healthily

A healthy lifestyle with healthy eating habits is important for everyone. It can also be considered as a preventative measure to prevent 'latent' TB infection becoming 'active' TB disease, and may prevent many other health problems. After a period of illness, it is important to eat the right foods to aid convalescence.

Nutrition plays a key role in maintaining a healthy lifestyle. According to Jane Rowntree: " It is a very important issue; the body needs different sorts of nutrients to function effectively. A lot of people only look at their weight as a measure of how good their diet is. People may over eat and be overweight, but if they don't eat the right foods they can still be deficient in vital minerals. The overall picture of what people are eating is important. It's well-known that nutrition can affect the immune system".

Eating meat and fish may be important in the treatment and prevention of TB. A study of Asian immigrants in south London found that vegetarians who ate no fish, meat or dairy products were at least eight times more likely to develop active TB than those who ate meat or dairy products every day.

The outcome suggests that a deficiency of vitamin B12 (provided almost entirely by foods from animal sources or fortified foods) increases the risk of developing TB. Appropriate intake is necessary to keep your immune system as strong as possible. A lack of vitamin D can also affect the strength of your immune response.

Jane Rowntree adds: "There are sometimes problems getting all of the nutrients you need. Vitamin B12 is concentrated in a lot of animal foods, such as milk, eggs and cheese. If you are a vegetarian or a vegan there may be a problem. It is important to make sure that you are getting enough before you develop any deficiency symptoms. If you don't eat meat, fish or dairy products you can, for example, increase your intake of yeast extracts. These contain a high concentration of vitamin B12 and contain no animal by products. High levels of vitamin B12 are found in some breakfast cereals. A lot of them are fortified with vitamins and minerals in any case. Regular consumption will ensure adequate vitamin intake".

A simple solution is to take a multivitamin once a day. This will provide you with the recommended daily amount. It is important to note, however, that if you are planning any major dietary changes it is wise to consult a dietician. Your doctor will be able to refer you.

Keeping fit

If you started an exercise regime in isolation, try to keep it up once you have been discharged. You will find it beneficial and it may go some way toward convincing you that isolation was productive. It would be a shame to let all of the hard work go to waste! If you haven't been through the isolation experience, then the same goes for you too! A brisk half hour walk is good for your heart and lungs; if you can do more, all the better. Just be sensible about what you can realistically do. Also get plenty of sleep and rest when you need it.

And Finally...

Once the doctor has given you the “all clear”, it’s still common to fear that TB will return. Like everyone else, you may get a cold from time to time. Don’t immediately jump to the conclusion that it’s TB: this is easily done. It serves no purpose worrying unnecessarily. Be aware of your own body. Simply, give your doctor a sputum sample, and he or she will be able to tell you how you are doing, and allay your fears. You will still need regular check ups, and your doctor may carry out the occasional chest X-ray to ensure all is well.

Look to your future, and make plans. TB, like many bad experiences, can be turned into a positive life-changing experience. You may want to think about how you can use having had TB for the good of all. Perhaps you could share your story with other people and tell them how you survived TB? Or you could set up a “TB club” so people who are on treatment have somewhere to go where they can meet other people who have had the same experience? You could start writing a newsletter for people with TB in your area, or if you are very ambitious set up an organization so that the voices of people with TB are better heard. There is no end of things that you can do to help. And let’s face it, after what you have been through, once you have been cured, you truly will be an expert!

TB tips: diet

It is possible to eat well on a budget, but it can be hard. You need motivation and you have to know what you are buying. Buy lots of fresh foods regularly, and shop around! Don’t just go to your local super market, they may charge more and the food may not be as fresh as from a dedicated store. It is easy to get distracted in supermarkets by less nutritious convenience food. If you have a freezer, try cooking in bulk. This is very cost effective.

Eating foods high in vitamin B12 may help prevent TB. These include:

- Meat
- Fish
- Eggs
- Dairy products
- Wholegrain cereals
- Beans
- Wheatgerm
- Green vegetables
- Yeast extracts
- Fortified breakfast cereals
- Whole grain breakfast cereals (check label)
- Some soya milks

After a period of illness and/or isolation, you may want to go out drinking with your friends. Being able to socialize again will feel brilliant. However, high alcohol intake after a period of weakness, may affect your body’s repair mechanisms. Alcohol has no nutritional value and gives a false sense of energy. It can affect your appetite and lower the levels of vitamins in your body. Remember, a regular high intake may also adversely affect the regularity with which you take your medication.

If you have got any questions, ask a dietician!

Medication Chart

Name of Tablet	Week One							Week Two						
	M	T	W	TH	F	S	S	M	T	W	TH	F	S	S

MONTH _____

Week Three

M	T	W	TH	F	S	S

Week Four

M	T	W	TH	F	S	S

Personal Information

My TB nurse is:

My hospital doctor is:

My clinic address is:

Contact number:

E-mail: