

1: WHAT IS TUBERCULOSIS?

“Tuberculosis is on the increase and is responsible for the deaths of more than two million people a year.”

(The World Health Organisation)

Tuberculosis is a contagious disease. It is caused by a type of bacteria called *Mycobacterium tuberculosis* or *M. tuberculosis*. Bacteria are tiny 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.”¹ 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. A definition that is more immediate is: “Tuberculosis is an infectious disease that usually attacks the lungs - but TB can attack almost any part of the body. It is spread from person to person through the air. When people with TB in their lungs (pulmonary tuberculosis) cough, laugh, sneeze, sing or even talk, the germs that spread TB may be spread into the air.

If another person breaths in the germs there is a chance that they will become infected with tuberculosis.”²

Left untreated or not treated properly, tuberculosis can kill. “Tuberculosis kills more youth and adults than any other infectious disease in the world today. It is a bigger killer than malaria and AIDS combined, and kills more women each year than all the combined causes of maternal mortality. It also kills 100,000 children each year.”³ The good news is that tuberculosis is a disease that we know a lot about and can cure...if it is treated properly.

WHO CAN GET TUBERCULOSIS?

Absolutely anyone can be infected with tuberculosis - even some animals. Some groups of people are at a higher risk of developing TB disease. These include:

- *People who share the same breathing space.*
- *People with poor nutrition.*
- *Homeless people.*
- *People who come from countries where there is a high incidence of tuberculosis.*
- *People in nursing homes.*
- *Prisoners.*
- *People with alcohol dependency.*
- *Intravenous drug users.*
- *People with medical conditions such as diabetes or certain cancers.*
- *People with HIV or AIDS.*
- *People living in poor and overcrowded living conditions.*

According to the World Health Organisation, *one third* of the world's population is already latently infected; one person is infected with tuberculosis each *second*.

TUBERCULOSIS: THE PAST

The story of tuberculosis puts fiction to shame. It may surprise many to know that tuberculosis is “probably as old as the earth itself - surviving in the primeval mud at the very beginning of time.”⁴ Archaeological evidence of tuberculosis has been found in fossilised bones. Hippocrates (460-375 BC), the Greek physician, called the disease ‘phthisis’, a term formerly applied to many wasting diseases and 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 in this book, occasionally causes dramatic weight loss.

Tuberculosis can affect almost any part of the body, not just the lungs. Historically, one of the most common occurrences was the bacterium attacking the lymph glands, often in the neck. This was given the name ‘scrofula’, but was often called the ‘King’s Evil’, because of the widely-held belief that the touch of a royal hand would cure the afflicted person.⁵

In 1720, the English physician Benjamin Marten published “A New Theory of Consumption”. He described the disease as being caused by “wonderfully minute living creatures”.⁶ The bacterium was not officially discovered until over 160 years later.

In 1882, the scientist Robert Koch announced the discovery of a staining technique that enabled the visualisation of *Mycobacterium tuberculosis* under the microscope for the first time. ‘Staining’ means the use of dye to colour tissues or micro-organisms so that they show up easier for examination. Most bacteria, once stained, decolourise with the acid. *Mycobacterium* retains the stain and hence is called ‘acid fast’; *Mycobacteria* are therefore known as ‘acid fast bacilli’ (AFB). The discovery heralded a new and exciting era in medicine. Once the bacteria had been identified, it seemed that the battle could begin properly against this age-old adversary.

Another important development was the discovery by Doctors Calmette and Guérin of a ‘tamed’ living bacterium.⁷ ‘Tamed’ in the sense that it wasn’t particularly harmful and created the basis for a vaccine called BCG (“Bacille Calmette Guérin”). It is still in widespread use today. During the Second World War the most powerful weapons against tuberculosis were developed: the chemotherapeutic agents. Thereafter followed a stream of such treatments used to fight TB.

TUBERCULOSIS: THE PRESENT

“An alarming tide of new and resurgent diseases has been rising around the world for decades. Now it advances further than ever. This signals a crisis in the history of the human species. We have brought it on by rending the fabric of our environment, changing our behaviour and, ironically, by our inventiveness in increasing the length and quality of our lives - Ignorance is a destructive luxury when infections threaten to take more lives than war and famine.”⁸

Diseases once thought conquered by medical science are returning. Slowly but surely the rosy future presented by the wonder of antibiotics is beginning to collapse.⁹ The human race has been in existence for about 50 million years and the Earth for millions longer. Antibiotics have only been around for about the last 50 years, and unfortunately the weaknesses of this relatively new development are already becoming apparent.

There is little doubt that antibiotics were a wonderful discovery. It is their indiscriminate use which has caused the problem.¹⁰ Many diseases which we thought were moving towards eradication due to antibiotic use have begun to resist our greatest ally. The bacteria are more sophisticated than we thought. Like any living organism they have to reproduce and ultimately secure their survival. To ensure this, they are learning how to survive the antibiotics we use against them.

Man and the micro-organism have always been in conflict. Throughout history our success has waxed and waned; there are as many failures as victories. The last 50 years have proved the most successful: the next 50 years may be a different story.

Alarmingly, some scientists claim that the early 21st century will be more reminiscent of the middle ages in terms of disease.¹¹ There are many previous unknown diseases, such as AIDS, Lassa fever and the disease caused by the Ebola virus, emerging alongside newly returning diseases such as tuberculosis. Some tabloid newspapers have speculated as to the origin of these new diseases: a biological conspiracy perhaps, or another planet, or the hand of God? Evidence, they say, for the wrath of the Almighty.

Some notable comparisons may be made between tuberculosis and other diseases with regard to resistance to treatment with antibiotics. However, unlike AIDS, Lassa and Ebola, it is a disease that we know a lot about. Its return cannot be put down to the hand of celestial beings. It is “man’s rending of the fabric of our environment” that has sadly caused the problems we now face with regard to tuberculosis.¹² Unfortunately, we have allowed it to return.

TUBERCULOSIS: THE FUTURE

Since the introduction of anti-tubercular treatments, the number of reported cases has steadily declined. The figures on all reported cases produced by the Public Health Laboratory Service for England and Wales have clearly shown this. Worryingly, there is a new trend. Since 1985 the number of reported cases has - with little fluctuation - plateaued. There seems to be little difference between the figures produced for 1985 and those for 1997. Twelve years of constant fighting against the disease should have produced a further decline in its incidence. This has not been the case.

In a press release in 1993, The World Health Organisation declared that TB was presenting a “global emergency”. The

disease was returning and, without prompt action, the problem threatened to get out of control.¹³ This was contradicted by the UK Health Secretary of the time, Virginia Bottomley, who announced that: “Tuberculosis has virtually been eliminated”. It has been estimated that this statement alone probably accounted for a 5% increase in case numbers. Family doctors all over the country failed to diagnose the cases of the disease that came their way because they assumed it couldn’t possibly be TB, so confident were they in the ministerial reassurance that TB was well and truly defeated.¹⁴

I confess that, like many people, I thought tuberculosis was a ‘disease-of-old’ and that it belonged to the age of Byron. So many effective cures had been around since the 1940s, surely a young man living in London in the 1990s couldn’t contract TB. I was wrong.

A press release issued by the World Health Organisation in March 1998 informed the following:

“It is estimated that between now and 2020, nearly one billion more people will be newly infected, 200 million people will get sick and 70 million will die from TB if control is not strengthened.”¹⁵

When a statement like this is made by such respected a body, there is clearly a problem arising that cannot be ignored. Why should this be happening with a curable disease?

As already mentioned, one reason for the return of TB is the organism’s ability to adapt, so that some drugs used to attack it become ineffectual. Another reason is the ease with which people can now travel globally, bringing the disease with them from areas of high prevalence. This is due to wider reaching, more efficient transport systems coupled with greater freedom of movement created by the opening of political borders.

In the document entitled *The Interdepartmental Working Group on Tuberculosis*, produced by the Department of Health in September 1998, we find that:

“The incidence of tuberculosis in the UK was at its highest at the beginning of the 19th century. It then fell considerably, even before the introduction of specific anti-tuberculosis measures such as chemotherapy (in the 1940s), and BCG immunisation (in the 1950s) helped to hasten the decline. Some slowing of the decline occurred in the 1960s in association with substantial immigration from parts of the world with high rates of tuberculosis such as the Indian sub-continent, although the incidence in the majority white population continued to decline. Several factors are thought to have contributed including demographic change (especially an aging population), continued high rates of tuberculosis among new immigrants and the effects of poverty and homelessness as well as, to a relatively small extent, the HIV epidemic.”¹⁶

MULTIDRUG-RESISTANT TUBERCULOSIS

In spite of what you may have read about tuberculosis “drug-resistance has been recognised since chemotherapy for tuberculosis first became available - it soon became evident that resistance rapidly emerged unless a combination of anti-tuberculosis drugs was used in treatment.”¹⁷ Bacterial resistance to medication is nothing new.

Strains of tuberculosis that are resistant to the initial treatment with two or more drugs (including isoniazid and rifampicin) are termed multidrug-resistant (or MDR TB).

Drug resistance can occur for a number of reasons. An individual can come into contact with an already drug resistant strain and subsequently develop MDR TB, or a patient may have a fully drug sensitive tuberculosis but demonstrate drug resistance during a course of treatment which is either inadequate or incomplete.

Farmers who use pesticides on their fields will tell you that, every couple of years or so, they have to change the pesticide they use to prevent resistance developing amongst the pests. The

TB bacterium may develop resistance in the same way. In cases where it hasn't been completely eradicated by treatment (for example, when a patient hasn't taken medication at the appropriate times), any remaining bacteria may develop resistance. If this happens, the patient may pass on a drug resistant strain.

The process is repeated endlessly, with drug resistant strains passing from person to person, failure to take medication appropriately, and the disease learning how to beat different drugs. Potentially, there is the frightening scenario where TB strains completely resistant to all medication emerge and circulate amongst the population as a whole. Correct compliance with medication is one way in which this may be halted.

TUBERCULOSIS AND HIV

Large numbers of the world's population, as mentioned earlier, are latently infected with TB. In other words, although the TB bacteria are present in the body the disease does not develop, remaining 'dormant' (after the manner of a dormant volcano, so to speak). If for any reason the immune system is weakened, the bacteria are no longer held in check, and the disease develops. This is typically the case of people with HIV.

Tuberculosis is, for the most part, a treatable and curable disease. AIDS is becoming more treatable - but at present is not curable. As with many infectious diseases social stigmatization is brought into play. And for some, the fear of the stigmatization attached to both of them combined is unbearable.

Some have termed having AIDS and tuberculosis as "the Devil's Alliance". It is an apt title. "Tuberculosis in patients with co-existing HIV infection may develop the disease more rapidly."⁸ However, there is no evidence to suggest that HIV infected individuals with tuberculosis are more infectious than non-HIV infected people.

It was with a certain irony that in the introduction to my first book, *Positive Carers* I wrote: "...as people strive to develop cures and to conquer disease, it is unlikely that they will ever succeed in eradicating all harmful organisms from the environment. Indeed, just as we were getting used to the idea of effective control over bacterial infection through the miracle of antibiotics, there is growing evidence of more virulent strains of bacteria which have genetically acquired resistance to multiple drugs. For example, in the US a strain of tuberculosis has been observed which is resistant to virtually all the available antibiotics. A relationship based on an inter-dependency between humans and micro-organisms exists, with one achieving dominance over the other."⁹

Little did I know that what was written then was to become part of my future. I later contracted multidrug-resistant TB on top of my AIDS diagnosis, and was about to live with and fight the 'Devil's Alliance' myself, as the diary which I kept throughout that time will show.

To conclude this section, here are a few of the more famous public figures from the pages of history who have suffered with tuberculosis:

- *Napoleon II, King of Rome, Duke of Reichstadt (1811-1832)*
- *King Louis XIII, King of France (1601-1643)*
- *King Amenophis IV and his wife Nefertiti (1360BC)*
- *Marquise de Pompadour (1721-1764)*
- *Henri Purcell (1658-1695)*
- *Nicolo Paganini (1782-1840)*
- *Igor Stravinsky (1882-1971)*
- *Edward Grieg (1843-1907)*
- *Frederick Chopin (1818-1848)*

- *Vivien Leigh (1913-1967)*
- *D.H. Lawrence (1885-1930)*
- *George Orwell (1903-1950)*
- *Robert Louis Stevenson (1850-1894)*
- *Emily Bronte (1818-1848)*
- *Anne Bronte (1820-1849)*
- *John Keats (1795-1821)*
- *Anton Chekov (1860-1904)*
- *St. Therese of Liseux (1872-1897)*
- *Carl Maria Von Weber (1786-1826)*

Nobody is totally 'immune' to tuberculosis; everyone's potentially susceptible.