

# Tuberculous (TB) Meningitis

## The Facts

This fact sheet provides information about tuberculous (TB) meningitis and answers some frequently asked questions. This should be read in addition to our 'What is meningitis?' leaflet, which provides more information on signs and symptoms and emergency action to take. You can request a copy by contacting our 24-hour nurse-staffed helpline on **0800 028 18 28**.

Words highlighted in **blue** are explained in a glossary on the back page.

### What is TB meningitis?

TB meningitis is a life-threatening infectious disease that causes **inflammation** of the layers that surround the brain and spinal cord. These layers are called the **meninges** – they help to protect the brain from injury and infection.

TB meningitis is caused by the bacterium *Mycobacterium tuberculosis*. Infection with this bacterium begins elsewhere in the body, usually the lungs, but in about 2% of cases the bacteria travel via the bloodstream to the meninges and cause TB meningitis.

Unlike other types of meningitis that develop quickly, e.g. meningococcal or pneumococcal, TB meningitis usually develops slowly with vague symptoms such as aches and pains, loss of appetite and tiredness, usually with a persistent headache. These vague symptoms can last for several weeks before the more specific symptoms of meningitis such as severe headache, dislike of bright lights and neck stiffness occur. The slow progression of the disease makes it difficult to diagnose and it is often advanced before treatment begins.

### Key points

- There has been a steady increase in the number of TB meningitis cases in recent years
- TB meningitis usually develops slowly
- TB infection usually begins in the lungs and in about 2% of cases the infection can progress to TB meningitis

### How many cases of TB meningitis are there each year?

There has been a steady increase in the number of notified cases of TB over recent years, from 6,300 cases in 2000 to 8,650 cases in 2008. In 2008, there were over 200 reported cases of TB meningitis in the UK.

### Can TB meningitis be prevented?

Yes, there is a **vaccine** known as BCG. This vaccine is effective in babies and young children. It gives good protection against the more severe forms of TB, such as TB meningitis.

BCG vaccine used to be offered to all children at secondary school in the UK. Due to changes in the distribution and occurrence of TB in the UK, the vaccine is now offered to those individuals who are at greatest risk. The current programme of vaccination targets babies, children and older people who are most likely to catch the disease. The vaccine is also recommended for healthcare workers who may be exposed to TB.

For more information about the BCG vaccine, please visit [www.immunisation.nhs.uk](http://www.immunisation.nhs.uk).

## Who gets TB meningitis and why?

Anyone can get TB and therefore TB meningitis, but it is more likely to affect those living in poor conditions such as the homeless, and those with other illnesses, especially HIV infections. In areas of the world where the incidence of TB is high, TB meningitis is most common in children under 5 years of age. Where the incidence of TB is low, most TB meningitis cases are in adults. The following areas of the world have a high incidence of TB:

- Africa
- South East Asia
- Eastern Mediterranean
- Western Pacific

People working or travelling in these areas should seek advice about BCG vaccination.

## What happens in the body?

The development of TB meningitis occurs as follows:

- Tuberculosis **bacteria** enter the body by droplet inhalation i.e. breathing in bacteria from the coughing/sneezing of an infected person
- The bacteria multiply within the lungs, pass into the bloodstream and are able to travel to other areas of the body
- If the bacteria travel to the meninges and brain tissue, small abscesses (**tubercles/microtubercles**) are formed
- These abscesses can burst and cause TB meningitis. This can happen immediately, or several months or years after the initial infection
- The infectious process causes a rise in pressure within the skull, resulting in nerve and brain tissue damage which is often severe

In the early stages of the disease, the symptoms are often non-specific and include:

- Persistent headache
- Vomiting
- Fever

These symptoms may be present for several weeks whilst the disease is developing. The later, more specific symptoms include:

- Severe headache
- Dislike of bright lights
- Neck stiffness
- Confusion
- **Nerve palsy**
- Fitting

## How is TB meningitis treated?

TB meningitis requires admission to hospital and close monitoring to assess the progression of the disease. Each patient will be individually assessed and their care planned accordingly. A variety of investigations and procedures may be necessary.

One of the main investigations carried out to test if someone has meningitis is a **lumbar puncture**. This allows the doctor to make a diagnosis of meningitis by analysing the **cerebrospinal fluid (CSF)** that bathes the meninges. This fluid becomes infected when a patient has meningitis.

All patients will be given a combination of antibiotics to treat the infection. In the UK, isoniazid, rifampicin, pyrazinamide and a fourth drug (e.g. ethambutol) are usually given for the first two months, followed by isoniazid and rifampicin for the next ten months. This combination is given to reduce the risk of antibiotic resistance developing. Treatment may vary according to the response of the individual patient. Drug resistant TB meningitis may require long schedules of treatment with a variety of alternative antibiotics. A **steroid** (e.g. prednisolone) is also often recommended for the first few weeks of treatment.

It is essential that the full course of treatment is completed. This will reduce the risk of the disease returning and of the bacteria becoming resistant to the antibiotics.

## What happens when there is a case?

In order to develop TB meningitis a person will have acquired the bacteria via the lungs and may therefore have active TB in areas of the body other than the brain. Contacts of the person with TB meningitis will be offered testing and, where appropriate, antibiotic treatment and/or BCG vaccination. It is possible for a person to be infected with the TB bacteria but not develop TB disease. This is known as latent TB because the TB bacteria are not active in the body. The person is usually well and cannot pass the bacteria to other people. However, there is a risk that latent TB may develop into active TB and for this reason latent TB is still treated with antibiotics but for a shorter length of time.

## What happens after TB meningitis?

Due to the slow progression and non-specific early symptoms of TB meningitis, diagnosis can be difficult. However, research has shown that early diagnosis and treatment can significantly improve the outcome of the disease.

If treatment is started early, most people will make a good recovery provided that the treatment course is completed.

At least 20% will suffer long-term after-effects. These are often severe and may include:

- Severe brain damage
- Epilepsy
- Paralysis
- Hearing loss or deafness
- Loss of sight or blindness

After-effects are often complicated and can require ongoing support (for life) from a wide range of health professionals and organisations. In many instances the after-effects will be helped by various types of therapy, e.g. physiotherapy and occupational therapy.

Other people may experience a wide range of less debilitating, but serious, after-effects. These can be temporary or permanent and include memory loss, anxiety, depression and headaches. Whatever the after-effect, mild or severe, meningitis can change a person's life forever.

Tragically, between 15-30% of patients will die despite receiving treatment and care. The death of a loved one from meningitis is always painful and traumatic. If you have lost a loved one, our trained helpline nurses are available 24 hours a day, and can explain how we may be able to offer you support.

More detailed information about the after-effects of meningitis is available in our 'After meningitis' booklet. You can request a copy by contacting our helpline on **0800 028 18 28**.

## Find out more

- **Meningitis Trust**  
[www.meningitis-trust.org](http://www.meningitis-trust.org)  
Information about meningitis and the work of the Meningitis Trust.  
[www.meningitis-learning.org](http://www.meningitis-learning.org)  
Learn more about meningitis by playing online quizzes and touring the virtual body invasion.
- **NHS Immunisation information**  
[www.immunisation.nhs.uk](http://www.immunisation.nhs.uk)  
Information about vaccination published by the Department of Health.
- **Meningitis a Guide for Families (1997)**  
J Simon Kroll, Andrew J Pollard, Parviz Habibi – Publisher, Publishing Solutions Ltd (UK).  
A recommended read for parents. This book provides excellent information and uses case studies to explain meningitis and meningococcal disease.
- **Need to know meningitis (2004)**  
Kristina Routh – Publisher, Heinemann Library. This comprehensive and easy to understand book traces the history, incidence and consequences of meningitis.
- **Disease statistics**  
[www.hpa.org.uk/infections/topics\\_az/tb](http://www.hpa.org.uk/infections/topics_az/tb)
- **TB Alert**  
[www.tbalert.org](http://www.tbalert.org)  
Information about TB, support for those affected in the UK and local partnerships in the developing world to raise awareness of the disease.

## Glossary

### Bacteria/bacterium

Single-celled micro-organisms, of which there are many types. Some types can cause disease in humans.

### Cerebrospinal Fluid (CSF)

A protective fluid that flows around the brain and spinal cord, helping to maintain healthy cells.

### Inflammation

A response of the body tissues to injury or irritation. The response is characterised by redness, swelling, heat and pain.

### Lumbar puncture

A procedure to remove CSF from around the spinal cord.

### Meninges

The protective membranes that surround the brain. These are called the dura mater, arachnoid mater and pia mater.

### Microtubercle/tubercule

A small round nodule produced by infection with TB bacteria. In the brain these are called Rich's foci.

### Nerve palsy

Paralysis caused by damage to, or pressure on, a nerve.

### Steroid

A medicine given to reduce inflammation.

### Vaccine/vaccination

An injection given to encourage the body to produce antibodies which help to fight infectious disease. The injection contains small particles of the disease causing organism.

## The Meningitis Trust

We, the Meningitis Trust, are a registered charity set up in 1986 by families who had been affected by meningitis. We are committed to increasing understanding of the disease and providing specialised professional services to anyone who has been affected. These services offer emotional, practical and financial support to help people rebuild their lives.

Here are some of the ways we do this.

**24-hour helpline** – a Freephone service, staffed by nurses, providing information and support seven days a week

**Home visits** – trained staff offer information and support in people's homes

**Art therapy** – allows children and young adults to use art to help them express how they are feeling in safe and confidential surroundings

**Professional counselling** – confidential counselling for people who have had meningitis and their families

**Financial support grants** – to help fund specialist training, equipment, activities, respite care (to give carers a break from caring) and funeral costs

**One-to-one contacts** – putting people affected by meningitis in touch with volunteers who have also experienced the disease

This is only made possible by donations from people like you, as we rely almost entirely on voluntary support to fund our work.

**If you have any questions or wish to discuss anything in this fact sheet in more detail, please phone our helpline.**



helpline staffed by nurses

**0800 028 18 28**

**www.meningitis-trust.org**

Calls from BT landlines are free. Other service providers and mobile rates may vary.



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