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 'Meningitis can affect anyone' leaflet, which provides more information on signs and symptoms and emergency action to take. All our information can be found at **www.MeningitisNow.org**. You can also request any of our information materials by contacting our Meningitis Helpline on **0808 80 10 388**.

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

Key points

- 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
- A combination of antibiotics, given for 12 months, is needed to treat TB meningitis

What is TB meningitis?

TB meningitis is a life-threatening infectious disease that causes **inflammation** of the membranes that surround the brain and the spinal cord. These membranes are called the **meninges** – they help 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, tiredness, and 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.

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 only to those individuals who are at greatest risk. The current programme of vaccination in the UK targets babies, children and young people who are most likely to catch the disease. The vaccine is also recommended for individuals at occupational risk e.g. healthcare, laboratory and prison workers.

For more information about all available vaccines to prevent meningitis download a copy of 'Meningitis vaccines, the facts' from our website or call the helpline.

For more information about the BCG vaccine, visit https://www.nhs.uk/conditions/vaccinations/bcg-tuberculosis-tb-vaccine/

Who gets TB meningitis and why?

Anyone can get 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. In the UK incidence of TB is low and most TB meningitis cases are in adults.

The burden of TB is highest in the following countries:

- India
- China
- Indonesia
- Philippines
- Pakistan
- Nigeria
- Bangladesh
- South Africa

There are high numbers of people with multidrug-resistant TB in India, China and also Russia.

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

How does TB meningitis develop?

The development of TB meningitis occurs as follows:

- Tuberculosis bacteria typically 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 or lymphatic system 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**
- Convulsions/seizures

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 quickly 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 ethambutol are usually given for the first two months, followed by isoniazid and rifampicin for the next ten months. This combination reduces the risk of antibiotic resistance developing. Treatment may vary according to the response of the individual patient. A **steroid** (e.g. prednisolone) is also often recommended for the first few weeks of treatment. Drug resistant TB meningitis may require long schedules of treatment with a variety of alternative 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 active 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 may be treated with antibiotics, although generally with a shorter course than for active TB.

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 however some will suffer long-term after-effects.

Where TB meningitis is diagnosed at a late stage, between 25 to 50% will be left with long-term after-effects. These are often severe and may include:

- Acquired brain injury
- 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.

Other people may experience one or more of a wide range of less noticeable, but still significant, after-effects. These can be temporary or permanent and include memory loss, anxiety, depression, headaches, learning and behavioural difficulties.

A booklet 'Your guide' provides more information about the after-effects of bacterial meningitis and meningococcal septicaemia in children. To request a copy or find out more about after-effects and the support Meningitis Now can offer, go to www.MeningitisNow.org or call our helpline.

This booklet can also be downloaded at www.MeningitisNow.org/recovery

Tragically, some patients will die despite receiving the best possible treatment and care. The death of someone close following meningitis or septicaemia can be traumatic, distressing and painful. If someone close to you has died, our helpline staff are there to listen, and can explain the different ways we are able to offer help and support.

Find out more

- **Meningitis Now**
  www.MeningitisNow.org
  Information about meningitis and the work of Meningitis Now.

- **NHS immunisation information**
  www.nhs.uk/conditions/vaccinations/
  Information about vaccines and NHS immunisation programmes.

- **TB Alert**
  www.tbalert.org
  Information about TB, support for those affected in the UK and local partnerships in the developing world raising awareness of the disease.

Glossary

Bacteria / bacterium
Single-celled micro-organisms, of which there are many types. Some types can cause disease in humans. One organism is called a bacterium and more than one are called bacteria.

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 below the base of the spinal cord.

Meninges
Three protective membranes (layers of tissue) 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
A preparation, usually an injection, given to encourage the body to produce antibodies which help fight infectious disease. The preparation commonly contains a harmless extract prepared from the disease-causing organism.

Meningitis Now is here to help you. We are saving lives and rebuilding futures through awareness, research and support.

We offer ongoing support for all those living with the impact of the disease. We support individuals, and their families, including those who have been bereaved, helping to rebuild lives after meningitis and meningococcal septicaemia.

We can:

- Listen; and answer your questions about meningitis and meningococcal septicaemia
- Talk to you about your individual experience and how we can tailor our help to you
- Provide support locally to you
- Put you in touch with others who have been through it too
- Support you and those closest to you; children, teenagers and adults
- Provide financial contributions towards unexpected costs following meningitis through our Rebuilding Futures Fund

If you have any questions, or are interested in finding out how we can help, please get in touch.

Meningitis Helpline: 0808 80 10 388 (UK)

Email: helpline@meningitisnow.org

We are proud of the work we do, but we can't do it alone. We rely on voluntary donations and need help from people like you. Every penny, pound, hour and day given makes a big difference. Find out how you can help **www.MeningitisNow.org**

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References for the content of this fact sheet are available on our website.

Meningitis Helpline
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