After meningitis

A guide to:

• life after meningitis and meningococcal septicaemia; and

• support available from the Meningitis Trust.

Helpline 0845 6000 800

www.meningitis-trust.org
Introduction

Meningitis and meningococcal septicaemia are serious diseases that can affect anyone at any time. Most people who get meningitis and septicaemia will make a full recovery, but sometimes there are after-effects and complications.

We, the Meningitis Trust, have designed this booklet to give an overview of the after-effects and problems that people experience. It also provides important information about the support we can offer and shows how we can help individuals and their families come to terms with life after meningitis.

We have been working with and supporting people affected by meningitis and septicaemia since 1986. We have built up a great deal of knowledge and understanding of the effect the disease can have. Although we realise there is no quick fix, the emotional and practical support we provide can be invaluable.

One of the most devastating outcomes of meningitis and septicaemia is death. There are many ways in which we can offer help and support for those bereaved. If you have lost a loved one, our trained staff are here to listen 24 hours a day - please call 0845 6000 800.
About after-effects

This section gives an overview of the most common after-effects people experience after meningitis and septicaemia, and tells the real-life stories of sufferers.

After-effects and complications can happen with any type of meningitis but are more common after bacterial meningitis. The exact number of people experiencing after-effects is not known, but we estimate that 15% of sufferers are left with serious disabilities and many more will suffer a range of short-term or less serious problems. The length and severity of after-effects varies depending on the type of meningitis. For example, pneumococcal meningitis and meningitis in newborn babies are more likely to cause serious complications.

Because viral meningitis is very rarely life-threatening many sufferers can feel that their illness is taken less seriously and the after-effects they suffer are not always acknowledged. Recovery from viral meningitis can be very slow but is normally complete. However, sufferers can still get headaches, tiredness, depression, memory loss and concentration problems.

We estimate that 75% of sufferers make a good physical recovery.
Emotional difficulties

Following what can be an extremely traumatic experience the emotional effects on individuals and their families can be huge, even with a good physical recovery. People say that their emotions change from day to day and it is important to remember that everyone will respond to their illness differently.

Emotional difficulties will vary depending on age. For example, young children often experience nightmares, bed wetting, clingingness and temper tantrums. Teenagers can go through a period of depression and find it difficult to express their emotions. Children and adults may experience anxiety and depression, lack of self-esteem and confidence, and behavioural problems such as aggression and mood swings.

Many families find it difficult to cope with the challenging emotional effects when there is not always an easy answer to the problems. At this time, patience and understanding is often the best way forward. Some people may need more support to get them through the bad times.
After meningitis

The after-effects of meningitis usually happen because of damage to areas of the brain including the nerves responsible for hearing and sight. The serious and disabling after-effects are well recognised and include: hearing loss or deafness, loss of vision or blindness, epilepsy, severe brain damage, speech problems, learning difficulties and behaviour problems. Some of these after-effects may also happen as a result of brain damage following septicaemia.

Hearing loss

Hearing loss is the most common after-effect of meningitis. Hearing difficulties can range from mild degrees of hearing loss through to profound deafness in one or both ears. Damage to the inner ear can also result in balance problems and tinnitus (ringing in the ears). Hearing loss may not be immediately obvious. It is important that anyone who has had meningitis has a hearing test soon after their illness. If you have not had a hearing test, contact your GP. If you have a hearing loss, you will be referred to an audiology centre where you can get appropriate help and support as soon as possible.

All hearing losses are different. Hearing tests may need to be repeated. You can get more information about hearing loss in children in our Meningitis and Childhood Deafness leaflet. For a copy call our helpline.
My story

Portia Hampton contracted pneumococcal meningitis. As a result, she has been left profoundly deaf with serious balance, eyesight and speech problems. Portia has overcome many hurdles and has learned to walk again as well as learning to sign with her nine-year-old daughter, Carys.

"For a long time I grieved for the person I was before meningitis and didn’t want to acknowledge the new deaf me. Without the support I received from my family and the Meningitis Trust I would have been truly lost. I was able to talk through my feelings and fears to someone who really understood. It was so reassuring to be told that what I was going through was all part of the recovery process after meningitis."

Portia Hampton
Loss of sight

Meningitis can damage the nerve responsible for sight (optic nerve), resulting in partial loss of vision or blindness in one or both eyes. Many people experience eyesight difficulties due to the optic nerve swelling after their illness. Commonly this does improve over time. If you are experiencing sight problems, you should be referred to an ophthalmology department for further treatment and support.

Severe brain damage and epilepsy

Severe brain damage following meningitis is not common and is usually obvious within a few days of becoming ill. The level of damage to areas of the brain may not be clear early on and it may take some time for health professionals and families to understand the full implications.

Hospital staff should explain what the outcome may be and the type of help and support needed.

Epilepsy (fits) can happen in a small number of people. It is not always immediately obvious and, occasionally, children and adults who have recovered from meningitis go on to develop epilepsy, which needs long-term medication.
Learning difficulties and behaviour problems

Learning difficulties and behavioural problems seem to be quite common after meningitis, especially in babies and young children. Fortunately, many of these sort themselves out on their own. However, some are permanent. Anyone who has had a serious illness and has been in hospital may experience behaviour and personality disturbances.

Long-term problems such as aggression and personality changes are often associated with severe brain damage.

When problems are more subtle, for example, irritability, difficulties concentrating, clumsiness, temper tantrums and sleep disorders, it is sometimes difficult to be sure that these problems are caused by meningitis. It is not always easy to get the right help and support.

When learning and behaviour difficulties are long-term, you usually need expert help and support. Many health professionals including GPs, paediatricians, psychiatrists and psychologists can help to reduce problems as far as possible and make life easier. Patience and understanding from family, employers, schools and those working with sufferers is vital.