Meningococcal disease, the facts

Meningitis and septicaemia

This fact sheet provides information about meningococcal disease (meningitis and septicaemia) 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.

What is meningococcal disease?

Meningococcal disease is a life-threatening infection. It is a term used to describe two major illnesses – meningitis and septicaemia. These can occur on their own or more commonly both together. Most people will make a good recovery but at worst meningococcal disease causes very severe illness that can rapidly result in death. Septicaemia is generally more life-threatening than meningitis.

Meningitis is **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.

Septicaemia is a severe infection of the blood. **Bacteria** multiply in the blood, releasing **endotoxins** that cause widespread damage to the body.

Meningococcal disease is caused by a bacterium called the meningococcus. There are five main groups; A, B, C, W and Y, that cause disease around the world. In the UK, group B causes the majority of disease.

Can meningococcal disease be prevented?

Yes, some groups of meningococcal disease can be prevented with **vaccines**. Vaccines are the only way to prevent infectious illnesses such as meningococcal disease.

Key points

- Meningococcal disease is a life-threatening infection.
- Men B vaccine was introduced into the routine immunisation schedule in Sept 2015
- Due to the rise in Men W cases, all 14 – 18 year olds are being offered a Men ACWY vaccine

A **Men C** vaccine, routinely offered at 12-13 months, is available as part of the **routine immunisation schedule** to protect against meningococcal group C disease.

A **Men B** vaccine, to protect against meningococcal group B disease, was introduced into the routine immunisation schedule in September 2015. A total of three doses are given at 2, 4 and 12 months of age. The vaccine is also available on the NHS for a small number of children and adults who are at increased risk of meningococcal infection, including those with no spleen or those who have a disorder of the immune system called complement deficiency. It is also possible to obtain this vaccine privately.

A **Men ACWY** vaccine routinely offered at around 14 years of age, is now part of the routine immunisation schedule. There is currently a catch-up programme to ensure this vaccine is also offered to all 15 – 18 year olds. Older university entrants (aged 19 – 25 years) are also eligible for this vaccine. It protects against meningococcal groups A, C, W and Y.

Men ACWY is also available as a travel vaccine for people visiting parts of the world where they are at increased risk of contracting meningococcal disease.

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

Who gets meningococcal disease and why?

Meningococcal disease can affect any age group, but young children and particularly babies under the age of one are most at risk, with teenagers and young adults being the second most at risk group.

Both adults and children can carry meningococcal bacteria harmlessly in the back of the throat. Around 10% of the general population will be carriers at any given time and nearly everyone develops **immunity** as a result of carrying these germs. Bacteria are passed from person to person by coughing, sneezing and intimate kissing.

Babies and young children are more at risk because their body's defences are not fully developed. If the bacteria invade the body their immune system cannot provide resistance to fight off infection. A risk factor for teenagers and young adults is increased social interaction; this increases the number of carriers to around 25%. People over 55 are the third at risk group, when the ability to fight off infection begins to decrease.

How does meningococcal disease develop?

Occasionally meningococcal bacteria defeat the body's defences and cause infection. The bacteria break through the lining at the back of the throat and pass into the bloodstream. Here they start to multiply rapidly, doubling in number around every 30 minutes. They can travel in the bloodstream to infect the meninges, causing meningitis, or whilst in the bloodstream they can cause septicaemia.

Meningococcal meningitis

When the bacteria infect the meninges, tiny blood vessels in the membranes are damaged. This allows the bacteria to break through and infect the **cerebrospinal fluid (CSF)**. The meninges become inflamed and pressure around the brain can cause nerve damage. Pressure on the brain can produce the specific symptoms associated with meningitis such as:

- Severe headache
- Dislike of bright lights (photophobia)
- Neck stiffness
- Nausea and vomiting
- Confusion and drowsiness
- Loss of consciousness
- Convulsions/seizures

Meningococcal septicaemia

As the bacteria multiply rapidly in the bloodstream, they begin to release endotoxins from their outer coating. The body's natural defences have little effect on these poisons and eventually blood vessels become damaged. This results in the more specific symptoms of septicaemia:

- Fever with cold hands and feet
- Joint or muscle pain
- Rapid breathing/grunting
- Stomach cramps, diarrhoea and vomiting
- Red/purple spots or bruises that do not fade under pressure

As septicaemia advances, it affects the whole body and can cause organ damage or failure. The rash associated with septicaemia is caused by blood leaking into the tissues under the skin.

Many other symptoms can occur with meningococcal disease. You can request our symptoms card by calling our helpline or download our free app at www.meningitisapp.co.uk.

How is meningococcal disease treated?

Meningococcal disease needs urgent treatment with antibiotics and rapid admission to hospital. If treated promptly, meningitis and septicaemia are less likely to become life-threatening. In hospital other treatment, procedures and investigations will be carried out depending on the patient's condition.

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 CSF that bathes the meninges. This fluid becomes infected when a patient has meningitis. Sometimes treatment with antibiotics is started because the patient's condition is too serious for a lumbar puncture to be performed. In these cases the lumbar puncture can be done when the patient's condition has improved.

If someone is seriously ill, they will require specialist care and treatment in an intensive care unit. Here the doctors and nurses can closely monitor their condition, respond to emergencies and provide immediate support when it is needed. Appropriate hospital care and treatment are essential if the patient is to make a good recovery.

What happens when there is a case?

Management of meningococcal disease in the community is the responsibility of a doctor who specialises in the public health management of infectious diseases. The public health team (doctors and nurses) will liaise with the hospital team in order to identify close contacts; these include household and family members, and intimate kissing contacts. Close contacts may be given antibiotics in order to reduce the risk of further cases. The antibiotics will kill any meningococcal bacteria being carried in the back of their throat, reducing the risk of further transmission. Close contacts may also be offered vaccination if a vaccine preventable group has been identified.

If two or more cases of meningococcal disease occur within four weeks of the first case, preventative treatment may be offered to more distant contacts. Each situation will be individually assessed and appropriate action taken. For example, if a second case occurs within four weeks in the same nursery school, all children and staff will be offered antibiotics, and vaccination if appropriate.

Most cases of meningococcal disease occur alone and the likelihood of a second related case is extremely small.

It is vital that accurate information is given following a case of meningococcal disease, as it can cause a high level of anxiety and fear. The public health team will liaise with local GPs, relevant schools/ nurseries or places of work to ensure good communication between all those concerned.

What happens after meningococcal disease?

Most people who get meningococcal disease make a full physical recovery, but around 15% will be left with severe and often permanent disabilities. However, the exact number of people who experience after-effects is not known.

The after-effects of meningitis usually happen because of damage to various 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.

After-effects and complications of septicaemia occur as a result of the toxins in the blood damaging vessels and stopping the vital flow of blood to the major organs of the body including the brain, kidneys, lungs, heart and skin. These after-effects include organ damage, areas of scarring, and loss of digits or limbs.

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

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 difficulties and behaviour problems. Whatever the after-effect, mild or severe, meningitis can change a person's life forever.

Our commissioned research (MOSAIC) shows that meningococcal disease can have a life-long impact, leaving a significant number of survivors with reduced IQ and problems with memory, concentration and organisation. The research has also shown that survivors are significantly more likely to experience mental health disorder and physical disability.

A journal is available to record a child's experience of meningitis and septicaemia, and offers detailed information about follow-up, recovery, after-effects and support.
To request a copy or find out more about after-effects and support Meningitis Now can offer go to www.MeningitisNow.org or call our helpline.

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
  Information about vaccination from NHS Choices.

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.

Endotoxins
Poisonous components of the cell walls of some micro-organisms e.g. bacteria. These poisons are released when the bacteria die and cause widespread damage to body tissues and organs.

Immunity / immune response
The body's ability to recognise and resist specific infectious diseases. The immune system responds to infection by producing antibodies.

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.

Routine immunisation schedule
A planned programme of vaccines which provides protection against a range of infectious diseases.
For more information, visit www.nhs.uk.

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

Meningitis Helpline
0808 80 10 388 (UK)

Meningitis Now is the UK's largest meningitis charity and is here to help you, when you need us and for as long as you need us. We are saving lives and rebuilding futures through awareness, research and support.

We offer practical, emotional and financial 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 septicaemia.

We can:

- Listen; and answer your questions about meningitis and septicaemia
- Talk to you about your individual experience and how we can tailor our help to you
- Visit you in your own home and provide support locally to you
- Put you in touch with others who have been through it too
- Provide financial assistance for unexpected costs following meningitis
- Support you and those closest to you; children, teenagers and adults
- Make you a priority; we have no waiting lists for our services.

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**

Meningitis Now
Fern House • Bath Road
Stroud • Gloucestershire • GL5 3TJ
Tel: 01453 768000 • Fax: 01453 768001
info@meningitisnow.org

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

© Meningitis Now July 2016 • Next review July 2017
Registered Charity Number 803016 (England & Wales) SC037790 (Scotland). Company Registration Number 2469130.

Meningococcal Outcomes Study in Adolescents and In Children

Commissioned by Meningitis Now* and led by Prof. Russell Viner, UCL Institute of Child Health

Published in The Lancet Neurology August 2012

Aims of the study

- to measure the physical, psychological, social and economic burden of meningococcal group B disease (meningitis and septicaemia)
- to estimate the after care needs of those affected to support the development of a nationwide standard of care and ensure Meningitis Now is providing the support that is needed
- to collect information that can be used to support the need for, and introduction of, a meningococcal group B vaccine.

From May 2008 to September 2010, 573 children and their families, from across England, took part. 245 children (cases) had suffered meningococcal group B disease (Men B) three years previously, when they were between the age of one month and 13 years. The other children (controls) had not suffered Men B. All children were assessed in the same way so that an accurate comparison could be made between the two groups. Each person's experience of the disease will be slightly different, but the following results show the *average effects* of Men B.

Results

Cognitive skills

Children and young people who have survived Men B are significantly more likely to have:

- a borderline low IQ (<85), both verbal and non-verbal
- deficits across all aspects of memory and sometimes in multiple aspects
- poorer executive function leading to problems with organisation and planning

*Meningitis Now is the new name for Meningitis Trust and Meningitis UK.

Physical
The following physical limitations and after-effects were reported in the survivors of Men B:

- hearing loss – five times more likely to have a significant hearing impairment, with 2.4% survivors having bilateral hearing loss requiring a cochlear implant
- amputation – significant amputation with disability in three cases and finger/toe amputation in a further two cases
- epilepsy – significantly more likely compared to controls
- speech and communication problems – five times more likely compared to controls

Mental health
One in five children and young people who have survived Men B have anxiety and behavioural disorders.

Summary
More than a third of children who have survived Men B have one or more problems with cognitive, physical and psychological function.

How will the results be used?

- the results of this unique study have already been presented, as evidence of the burden of Men B, to the Joint Committee on Vaccination and Immunisation (JCVI). This is an independent, expert advisory committee that advises the Department of Health on the provision of vaccination and immunisation services
- the results were used by Meningitis Now to support a campaign (launched October 2011) for regular educational assessments for all children and young people who have had meningococcal disease
- The results will also be used to inform health and education professionals about the long term impact of Men B so that children and young people are effectively supported

Support for life
Meningitis Now provides support for life to anyone living in the UK who has been affected by meningitis. If you have concerns or would like support you can call our helpline 0808 80 10 388 or visit www.meningitisnow.org to find out how we can help you.

July 2016

BIG LOTTERY FUND
LOTTERY FUNDED

Garfield Weston FOUNDATION
Funding for charitable organisations