



## Meningococcal meningitis and septicaemia

- ◆ Meningococcal infection is the most common cause of bacterial meningitis in the UK and Ireland<sup>1</sup>
- ◆ Meningococcal bacteria (*Neisseria meningitidis*) can cause meningitis or septicaemia, or a combination of these diseases
- ◆ There are several strains or 'groups' of meningococcal bacteria (A, B, C, W, X and Y). In the past 50 years, most meningococcal disease in the UK and Ireland has been due to both MenB and MenC<sup>2</sup>.
- ◆ Meningococcal disease affects around 2,000 people in the UK every year<sup>1</sup> and about 1700 are lab confirmed (annual average 2000-2010)<sup>3-6</sup>. Now that there is a very effective MenC vaccine, approximately 88% of all meningococcal disease cases are caused by MenB infection<sup>3</sup>.
- ◆ The disease can affect anyone of any age, but mainly affects babies, pre-school children and young people.
- ◆ Meningococcal meningitis and septicaemia are life-threatening diseases, but most people affected do recover. Septicaemia on its own is more likely to be fatal than meningitis<sup>7</sup>.
- ◆ Most survivors make a full recovery without long-term after effects, but around one in ten will be left with a major disability such as limb loss, deafness, epilepsy and brain damage. Approximately one third of survivors will be left with problems such as psychological disorders, reduced IQ and partial hearing loss. Survivors of meningococcal disease are more likely to have memory, planning and concentration problems than the general population<sup>8</sup>.

### Where does meningococcal disease come from?

The bacteria that cause meningococcal disease are common and live naturally at the back of the nose and throat. At any one time, one in ten of us carries the bacteria for weeks or months without ever knowing that they are there<sup>9</sup>, and for most of us this is harmless because fortunately most of us have natural resistance. They are passed from person to person through prolonged close contact: coughing, sneezing, breathing each other's breath or by kissing someone who is carrying the germ<sup>10</sup>. The bacteria do not naturally live or survive for long outside the human body.

### How do you get meningitis and septicaemia?

Only a small fraction of people who are exposed to meningococcal bacteria fall ill with the disease. The illness occurs when the bacteria break through the protective lining of the nose and throat, and enter the bloodstream. Once in the bloodstream, they multiply rapidly, doubling their numbers every 30 minutes. In some people, the bacteria cross the blood-brain barrier, causing meningitis. In others, overwhelming septicaemia happens so quickly that there is no time for meningitis to develop.

## What is septicaemia?

Septicaemia is the blood poisoning form of meningococcal disease. When meningococcal bacteria invade your bloodstream, they produce poisons. This makes you feel ill and feverish, and the poisons begin to attack the lining of your blood vessels, so that they leak. As blood fluids leak from blood vessels throughout your body, the smaller volume of blood that is left is not enough to carry oxygen to all parts of the body. Your lungs have to work harder, and in order to maintain circulation to your vital organs, your circulatory system reduces the blood supply to your hands and feet and the surface of your skin. This is how symptoms of septicaemia such as pale skin, cold hands and feet and rapid breathing develop<sup>11</sup>. As blood leaks into the surrounding tissues, this shows up on the skin as the typical non-blanching meningococcal rash. In most cases, rapid treatment stops the disease from progressing any further.

Sometimes the patient becomes very seriously ill by the time treatment starts, and the circulatory system is so overloaded that the patient collapses and needs urgent and aggressive resuscitation.

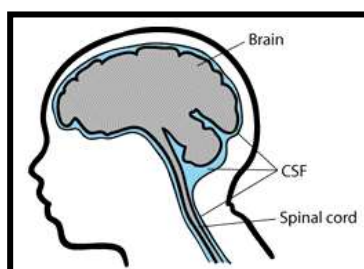
## What happens in very severe cases of septicaemia?

In very bad cases, septicaemia also causes blood clots to form throughout the network of tiny blood vessels in skin and muscle tissue. Tissue that is starved of oxygen this way dies and becomes blackened. This can cause widespread scarring, and in extreme cases can lead to amputation. This can also happen within vital organs, like your kidneys, causing kidney failure in very severe cases.

In the worst cases, even the best medical treatment cannot stop the disease from progressing and the patient dies. In recent decades, about one in five cases of meningococcal septicaemia has been fatal<sup>12</sup>, but quicker and better treatment is improving the chances of surviving<sup>13</sup>.

## What is meningitis?

When you get meningitis, bacteria that have invaded your bloodstream move across to infect your 'meninges' - the membranes that surround and protect your brain and spinal cord. The meninges are filled with a liquid called cerebrospinal fluid (CSF), which is there to bathe the brain and cushion it against physical damage when you hit your head.



Meningococcal bacteria can multiply freely in CSF, and there they release poisons, causing inflammation and swelling in the meninges and the brain tissue itself. This increases pressure on the brain, producing symptoms of meningitis such as headache, stiff neck and dislike of bright lights. As the disease progresses, individuals become drowsy, confused, and delirious. They may have seizures and eventually lose consciousness.

## **What happens in very severe cases of meningitis?**

In very bad cases, meningitis injures or destroys nerve cells and causes brain damage. This is due to the raised pressure on the brain and the toxic effect of the bacterial poisons on the brain cells, as well as reduced blood supply and formation of blood clots in blood vessels of the brain. All of these things can lead to after effects and disabilities such as epilepsy, learning difficulties, behavioural problems, problems with coordination or speech and movement disorders.

These effects may be temporary, but in some cases will be permanent. Sometimes, bacterial poisons also damage part of the inner ear (the cochlea), causing deafness.

Meningococcal meningitis is much less likely to produce long-term neurological damage and deafness than other kinds of bacterial meningitis. About one person in twenty with meningococcal meningitis dies from the disease<sup>14</sup>.

Septicaemia and meningitis affect the body in different ways, so they have different sets of symptoms. For symptoms information see Meningitis Research Foundation's 'Race Against Time' leaflet.

## **Who gets meningitis and septicaemia?**

About half of meningococcal disease occurs in children aged less than 5 years<sup>3</sup>, and babies are at the highest risk because their immune systems have not yet fully developed. There is a second, smaller increase in risk for older adolescents, mainly for social and behavioural reasons<sup>15</sup>. People with immune deficiencies, such as those without a spleen, are also at a higher risk from infection. Genetic factors play a role, but few of these have a strong effect<sup>16</sup>. Meningococcal disease is seasonal, with a peak during the winter months in the UK and Ireland.

## **How is meningococcal disease treated?**

Prompt recognition and treatment offers the best chance of a good recovery. A GP who suspects that someone has meningococcal disease will arrange for emergency transfer to hospital, and give antibiotics<sup>10</sup> or else ensure that antibiotics are given urgently by the ambulance paramedic or as soon as possible on reaching hospital.

Meningococcal disease must always be treated in hospital. Treatment may begin immediately if signs and symptoms of meningococcal disease are clear enough. If it is not clear what is wrong, the patient may be kept under observation at first. Along with a physical examination, blood will be taken for tests and the doctor may do a lumbar puncture. Lumbar puncture is important to confirm the diagnosis of meningitis, and to show which germ is causing the illness so that the most appropriate antibiotics can be chosen. If a patient with meningitis is very severely ill, it might not be safe to do a lumbar puncture right away, so this may be postponed. Having the diagnosis confirmed can be helpful afterwards, for example when seeking long-term medical advice and follow-up care.

Many patients need resuscitation when they get to hospital: oxygen is given and one or more intravenous lines put in to deliver medicines and resuscitation fluids. Patients with septicaemia may need large amounts of resuscitation fluid to bring their blood volume back to normal. Patients with meningitis may be given steroids to reduce inflammation and other medicines to lower pressure around the brain. Most patients are treated on a regular hospital ward, but the sickest patients will need intensive care treatment: about a quarter of children with meningococcal disease need treatment on a Paediatric Intensive Care Unit (PICU)<sup>17</sup>.

A patient being treated on a regular paediatric or adult ward will be closely monitored. The first couple of days and nights may be hectic and disturbed. The patient may be very drowsy or have many short naps, and may be miserable and irritable when awake. The course of antibiotics usually lasts for 7 days<sup>18</sup> so patients who respond well to treatment usually spend about a week in hospital. Some patients recover so quickly that they are able to go home after just a few days, either returning to hospital, or having a community nurse visit for their daily dose of antibiotics.

Very sick patients have to be transferred to intensive care. For children, this might mean a journey by mobile intensive care unit or ambulance to a specialist PICU. There, specialist doctors and nurses work around the clock to stabilise the patient and closely monitor their condition. The patient has to be sedated and put on a ventilator to help them breathe, tubes inserted, wires hooked up and connected to monitors, and more intravenous lines put in to deliver medicines that support the function of vital organs such as the heart, lungs and kidneys. Patients with septicaemia who need very large volumes of resuscitation fluid may look very bloated. However, when they start to recover this fluid will be reabsorbed into the circulation and got rid of through the kidneys. Most intensive care patients begin to improve after a few days and return to the regular wards. But very severely ill patients may have a prolonged stay, for weeks or even months.

### **What happens after meningococcal disease?**

Most people recover very well from meningococcal disease, with no long term after effects, but about a third of survivors are left with permanent after effects<sup>8</sup>. Some of these difficulties are temporary and disappear or improve with time. Behavioural and emotional effects are quite common: children can be clingy and have temper tantrums, adults can feel despondent and irritable. Although these feelings usually resolve themselves, psychological problems can be serious enough to need referral to mental health services or to a counsellor<sup>19</sup>. Parents of children affected by meningococcal disease may also need this kind of support<sup>20</sup>.

Such a severe illness, especially if there has been a long stay in intensive care, can leave the patient feeling weak and tired and much less active and mobile than before. They may also have problems with concentration, memory and attention and find it difficult to do tasks that seemed effortless before they became ill. In most cases, these difficulties gradually disappear.

### **What are the severe after effects?**

Meningitis can cause permanent neurological damage, ranging from minor problems with coordination and movement or mild learning difficulties, to epilepsy, paralysis, palsy and severe mental impairment. Deafness is the most frequent severe after effect of meningitis. Scarring, amputations and organ damage can result from septicaemia.

In the first few days of treatment for severe meningococcal disease, it is often impossible to tell whether there will be any permanent damage, but in most cases any serious problems become obvious while the patient is still in hospital.

### **What about follow up care?**

***It is recommended that all children who have had meningococcal disease are offered a hearing test as soon as possible (preferably before discharge) and certainly within four weeks of being well enough to undertake testing.*** Children should be reviewed by a paediatrician 4-6 weeks after discharge from hospital to discuss their progress and possible after effects associated with the condition<sup>18, 21</sup>. At this review the paediatrician will also discuss the results of the hearing test.

Occasionally, problems do not become noticeable until later. Learning difficulties and some coordination problems are hard to detect in babies and might not be discovered until a child reaches school age. Teachers should be informed when a child has had meningitis so that educational support can be arranged if necessary<sup>21</sup>.

Children who have had severe septicaemia with scarring or amputations may develop growth problems later on, and their growth should be monitored regularly<sup>22</sup>. In these cases, damage to bones and joints should be discussed at the review with the paediatrician after discharge and if necessary, children may be referred to an orthopaedic specialist.

Many people find it helps to talk to someone who has been through a similar experience and the Foundation's helpline team and befriending network are there to talk things over and provide a listening ear. For more detailed information on after effects, see the Foundation's booklet *Meningitis and Septicaemia, What Happens Next?*

## **Do people who have been in contact with meningococcal disease need treatment? Who decides?**

The risk to contacts is low. Although meningococcal disease is infectious, 97% of cases are isolated, with no links to any other cases<sup>10</sup> However, people who live in the same household as someone with meningococcal disease, and intimate kissing contacts (boy/girlfriends) are more at risk than other contacts. For this reason, these very close contacts of the patient are given antibiotics, usually ciprofloxacin or sometimes rifampicin, to kill the bacteria and help stop the disease from spreading. Usually family members who go with the patient to hospital will get antibiotics there. The local public health doctor then has the job of making sure that any other household or intimate contacts get antibiotics, and usually also tells the nursery or school the patient attends that there has been a case. There is no need to give antibiotics to a wider range of contacts, such as classmates, unless there has been more than one case within a short period of time. The public health doctor follows national guidelines<sup>10</sup> when deciding what needs to be done to protect the community.

It is important to remember that these antibiotics kill the bacteria that live in your nose and throat, but they cannot prevent illness in someone who is already incubating the germs. So even if you are given antibiotics, it is still important to look out for the signs and symptoms of septicaemia and meningitis. The charity's leaflet 'Am I at Risk' covers this topic and also explains the symptoms.

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