

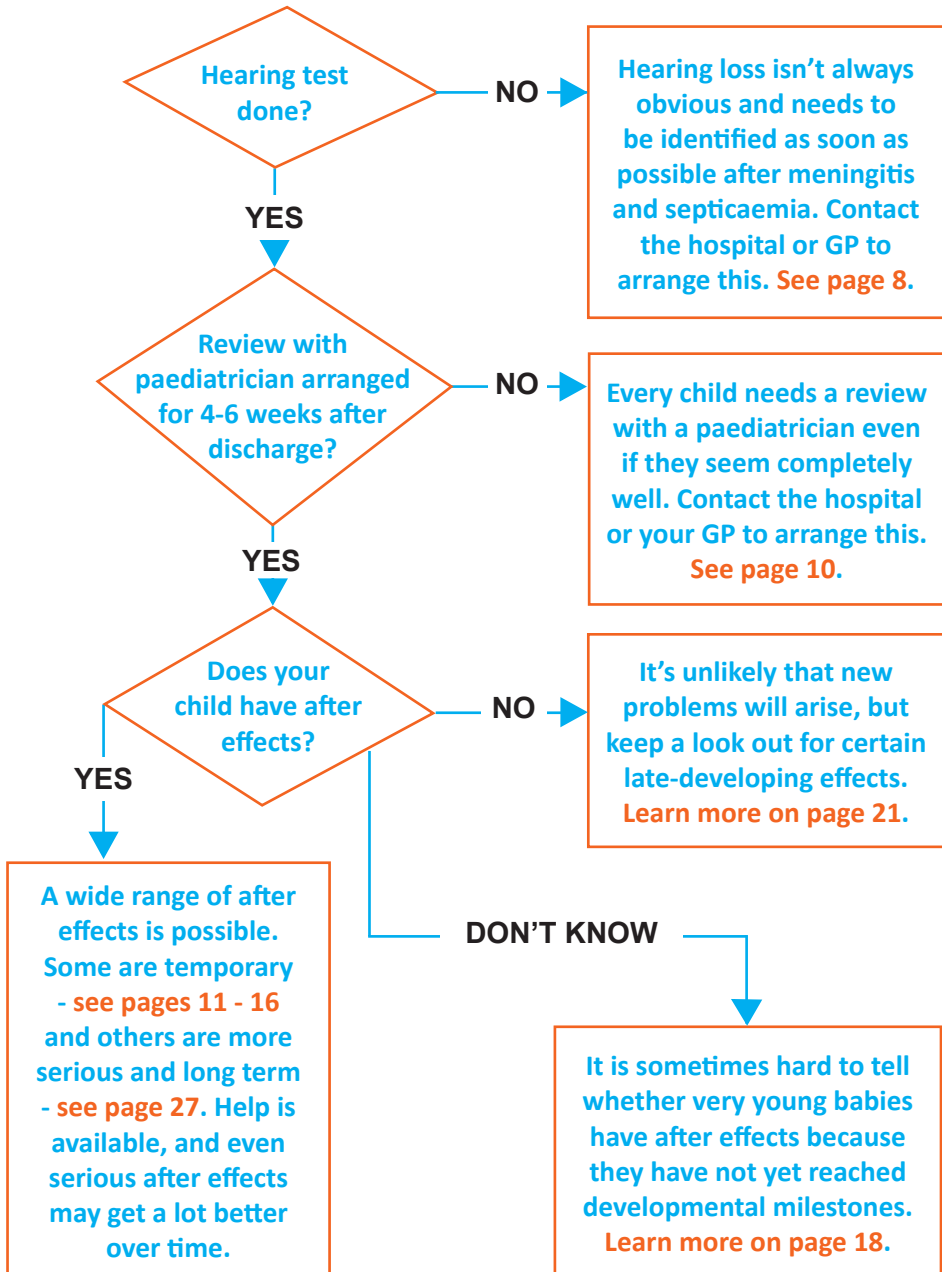


**Meningitis
now**

Your guide

Recovering from childhood bacterial meningitis and septicaemia

Your guide in brief



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Numbers within the text that appear as superscripts like this ¹² correspond with numbered references listed at the end of this guide on pages 37 and 38.

Meningitis Research Foundation free helpline 080 8800 3344

Meningitis Now free helpline 0808 80 10 388


Introduction

You are not alone. People are often unsure what to expect after meningitis and septicaemia. Parents of children affected tell us that discharge from hospital can be an anxious time because doctors and nurses are no longer on hand to answer questions. We hope that reading this will help ease anxiety for families at such a difficult time.



The rash caused by septicaemia was still visible when Leon left hospital, but it faded over time.

This booklet provides information about meningitis and septicaemia and their potential after effects. Most children who get meningitis and septicaemia survive without any permanent effects, so this booklet mainly focuses on some of the common temporary problems that children and families face soon after discharge from hospital. Fortunately, these issues commonly get better within a few weeks or months of being home from hospital.

This booklet is accompanied by a personal journal, which provides a place for parents and children to keep a detailed record about the illness, recovery and follow-up care. When you see this pencil icon  *please refer to My Journal which is available to download online at:-*

www.meningitis.org/After-Effects-Children

www.meningitisnow.org/myjournal

*In depth information about the more long-term or severe after effects from meningitis and septicaemia is available in **online factsheets** that you can print. They provide a personal reference for parents, children and young people.*



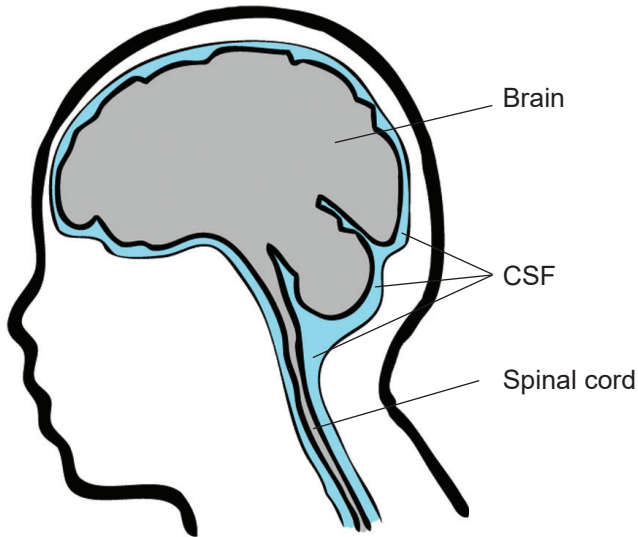
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Guidelines on managing children with meningitis and septicaemia recommend that healthcare professionals give parents and/or children who have been affected information about recovery, potential long-term effects and how to access follow-up care before they are discharged from hospital. These guidelines say that doctors should assess children for potential after effects and refer them for follow-up care and rehabilitation if this is needed. Guidelines from the National Institute for Health and Clinical Excellence (NICE)¹⁻² cover England, Wales and Northern Ireland, while Scotland is covered by the Scottish Intercollegiate Guidelines Network (SIGN)³.

What are bacterial meningitis and septicaemia?

Meningitis is inflammation of the membranes that surround and protect the brain and spinal cord. Septicaemia is blood poisoning caused by large numbers of bacteria in the blood stream. It is sometimes referred to as sepsis. Meningitis can be caused by various bugs such as bacteria, viruses and fungi. Most severe cases are caused by bacteria.



Bacterial meningitis occurs when bacteria invade the bloodstream and move across to infect the 'meninges' (the membranes that surround and protect the brain and spinal cord). The meninges are filled with cerebrospinal fluid (CSF), which is there to bathe the brain and cushion it against physical damage.

Bacteria can multiply rapidly in CSF, releasing toxins which cause inflammation and swelling of the meninges. This increases pressure on the brain, producing typical symptoms of meningitis such as headache and stiff neck. In the very worst cases this injures or destroys nerve cells in the brain and may damage the inner workings of the ear.

In septicaemia, the bacteria release toxins which attack the blood vessels so that they leak. As a result of these leaky vessels, the amount of blood reaching the vital organs decreases. To maintain sufficient oxygen supply to the vital organs, blood supply to the hands, feet and skin surface is reduced, and the lungs have to work harder. This is how symptoms of septicaemia develop. If the child is very seriously ill by the time treatment starts, the circulatory system may be so badly affected that urgent resuscitation is needed. In the very worst cases, septicaemia also causes blood clots to form within tiny blood vessels, which can damage the skin, fingers, toes, limbs or organs.

Many different types of bacteria can cause meningitis. For some people the specific cause of meningitis is never identified. The list below is by no means complete, but includes some of the more common bacterial causes:

- Meningococcus
- Pneumococcus
- Group B Streptococcus
- *E. coli*
- Listeria
- *Haemophilus influenzae*
- Tuberculosis (TB)

Meningococcal bacteria are currently the most common cause of bacterial meningitis in children in the UK. They can cause both meningitis and septicaemia, which children often have together.

More information about the specific types of meningitis, including viral meningitis, is available [online](#).

www.meningitis.org/causes

www.meningitisnow.org/causes

Can others catch meningitis from my child?

The risk of others catching meningitis from your child is very low. Most cases of meningitis and septicaemia occur in isolation because the bacteria do not spread easily from person to person.

All cases of bacterial meningitis and septicaemia should be notified to the local public health team by a clinician. Meningococcal and sometimes *Haemophilus influenzae* type b infections are the only types that need public health action after a single case to prevent the spread of disease.

In cases of meningococcal disease, the public health team will make sure that anyone at particularly increased risk of infection is offered antibiotics (usually ciprofloxacin). These antibiotics kill any meningococcal bacteria which might be carried by close contacts of the case and so prevent the spread of disease.

Only people who have had prolonged close contact with a case of meningococcal disease such as those living in the same household require antibiotics because the bacteria do not spread easily.

Meningococcal bacteria are commonly carried at the back of the nose and throat of healthy people and can be passed on by coughing, sneezing and kissing. Usually people have to be in very close or regular contact for the bacteria to pass between them and even when this happens most people will not become ill, because they have natural immunity to the bug. The bacteria do not naturally live or survive for long outside the human body.

Once your child has been treated with antibiotics, the bacteria will be killed and there will no longer be any risk of the infection being passed on. Despite this, family and friends can sometimes be anxious about risk of illness to them, and may avoid contact with you. This can be distressing, but if anyone is concerned about risk they can call the helpline numbers below.

Should my child be followed up after discharge from hospital?

Yes. Although most children make a good recovery, bacterial meningitis and septicaemia are serious infections. That's why the NICE guideline for bacterial meningitis and meningococcal septicaemia in children and young people¹ states that all children affected should have:

- A formal hearing test as soon as possible, preferably before discharge, or within four weeks of being well enough to test
- A review by a paediatrician **4-6 weeks** after discharge from hospital to discuss progress and possible after effects associated with the condition



Make sure your child gets these appointments. You can contact the hospital or make an appointment with your GP to arrange these.

It is important to attend both the hearing test and the six week review. Some parents are so relieved to get their child home from hospital that they do not want the upset of having to take their child back again for further appointments. However, missing the opportunity for follow up with the hospital can put your child at a disadvantage. Some after effects can be subtle and hard to identify. If your child has been affected by their illness it is better for any problems to be recognised early so that they can be treated as soon as possible.

Some children recover so quickly that they can go home after just a few days, either returning to hospital for their daily dose of intravenous antibiotics, or having a community children's nurse give their antibiotics at home.

Even if your child made a good recovery and was well enough to finish their course of antibiotics from home, a hearing test and paediatric follow-up appointment are still essential.

Why should my child have a hearing test?

Deafness is the most common serious after effect in children who have had bacterial meningitis. It usually happens early in the course of the illness and it may be noticeable to the family before the first hearing test. However, many cases of meningitis occur in children before they have learned to speak, so even severe hearing loss might not always be noticed by parents. Hearing loss in older children may also go undetected, especially if it is mild or affects only one ear.

It is vital for hearing loss to be identified as soon as possible after bacterial meningitis.

When meningitis damages the inner ear, it can cause the inner ear canals to rapidly harden, a process known as ossification. This can reduce the effectiveness of treatments to restore hearing. It is always important to identify hearing loss early in children because any level of hearing loss can be detrimental to your child's development.

If a hearing loss is identified, several options are available to help your child overcome this. Your child's audiologist (the specialist who carries out the hearing test) will discuss these with you.

There have been a few isolated reports of delayed hearing loss after bacterial meningitis⁴⁻⁵, although this is very uncommon. If you have any concerns about your child's hearing or feel that their hearing has changed since having the initial hearing test, you can ask your audiologist for another appointment, or ask your GP to refer you to the Ear, Nose and Throat (ENT) service.

If your child has hearing loss, more information on this is available [online](#).

www.meningitis.org/After-Effects-Children

www.meningitisnow.org/after-effects

What will the hearing test involve?

The type of hearing assessment offered will depend on your child's age and stage of development. For babies and children who are too young to answer questions or respond to behavioural tests, both the Otoacoustic Emission test (OAE) and the Auditory Brainstem Response (ABR) are commonly used. The OAE is part of the standard screening tests all babies have shortly after birth. A small earpiece is placed in the child's ear and a clicking sound is played. If the ear is functioning normally, a faint response will be picked up by the earpiece. In an ABR test an audiologist will place small sensors and a set of headphones on the child's head. This test measures whether sound is being sent from the ear, through the auditory nerve to the brain.



Most older children can be assessed with behavioural tests. This is where the child indicates that they hear a sound. Some children with complex needs may require techniques that are normally used with younger children. It is important for children with complex needs to have a hearing assessment. Hearing problems can have a 'multiplier' effect on a child's other disabilities, so it is important for these to be diagnosed and rectified as soon as possible. If your child has complex needs, you should be referred to a centre with experience of testing children with complex needs.

Why should we go back to see the paediatrician after leaving hospital?

The review with the paediatrician is an opportunity to raise any worries you have about your child's recovery, health or behaviour. The doctor should discuss the results of your child's hearing test with you and any after effects your child may have. They can refer your child to other services if required.

Even if your child has made a good recovery, it is vital to attend the review with the paediatrician.

The paediatrician will look for signs of after effects at this review. A range of different effects is possible: they can be mild or severe; temporary or permanent; physical or emotional. Most children recover without severe after effects. The more serious and long-term problems will usually be obvious to parents before discharge. See page 27 for information on serious and long-term after effects.

It is not always possible to be sure whether very young babies who have not yet reached many of their developmental milestones have significant after effects at discharge, or even by the time of your review with the paediatrician. For more information see page 18. If the paediatrician has any ongoing concerns about your child at this review they will arrange another appointment with you.

As a parent you know your child best. It is important to tell the paediatrician at this meeting if you have any concerns.

Note down any concerns you have after discharge in the journal so that you can discuss these with the paediatrician at the 4-6 week review. It may help to take photos/videos of things that concern you to show the paediatrician.



What issues might I face during my child's recovery?

It can take many months to recover from meningitis and septicaemia, although some children are back to their normal activities within a matter of weeks. We often hear from parents who are worried about their children when they first return home from hospital. Some common causes for concern are outlined below.

Anxiety that my child is becoming unwell again

It is completely normal to become more anxious about your child's health after a serious illness like meningitis or septicaemia. Some parents say that especially in the first few months, they worry that their child is getting meningitis or septicaemia again every time they catch a cold or have a fever. Viral illnesses are very common in young children, and it is very rare to get meningitis or septicaemia more than once. Nevertheless, keeping information about the symptoms of meningitis and septicaemia to hand can be reassuring for parents, and there is lots of information available [online](#).

www.meningitis.org

www.meningitisnow.org



If your child develops a fever, rash or limb pain within two weeks of being discharged from hospital then this needs urgent medical attention⁶.

In most cases, if such symptoms appear within 48 hours of leaving hospital, you can contact the paediatric team who treated your child. You should have hospital contact details on your child's discharge paperwork, which you can keep in your journal. The time limit for directly accessing the ward that treated your child will depend on the hospital, and how serious your child's illness was. The discharging paediatrician should let you know the time frame during which they would expect you to contact the ward if you have concerns. Beyond this time frame, or if you do not have the contact details for the paediatric team who treated your child, you should see your GP, or in an emergency take your child to A&E.

My child has headaches

Headaches are commonly reported amongst children who have recovered from meningitis, and they can last for months or longer after the initial illness. Although fairly common among children generally, there is evidence that headaches can be an after effect of meningitis⁷⁻⁸. If headaches persist, you should discuss them with the paediatrician at the 4-6 week review. If they continue beyond this review, then it is important to talk to your GP who can decide what further treatment might help, or if referral to a specialist is needed for further investigation.

My child tires easily

Children recovering from such a serious illness can feel weak and tired at first, or become tired very easily. It is also common for children to have difficulty sleeping for the first few months after discharge, so it is important to be aware of signs of fatigue. Older children may feel well as soon as they get home from hospital and don't realise that they may not be able to slot back into their normal life immediately. This can be very frustrating for them. It can be helpful in these circumstances to explain to your child that it might take a little more time to bounce back, and make sure they get the rest they need. It is also important to speak to your child's nursery or school about this so that they can help your child appropriately.

My child is behaving differently

Children often have problems with behaviour after meningitis and septicaemia, but usually these resolve over time. Some common behavioural problems (dependent on the child's age) are **temper tantrums, clinginess, bed-wetting, nightmares, mood swings, aggression, restlessness** and **an inability to settle down and concentrate**. These problems are probably due to a combination of physical and psychological factors. It is likely that for many children, tiredness makes things worse.

The experience of being severely ill is likely to be stressful for a child. Research has shown that children who were severely ill with meningitis and septicaemia experience stress and anxiety in the months after their illness⁹⁻¹¹.



Children may have intrusive thoughts; for example, memories of their time in hospital unavoidably popping into their mind. They may want to avoid anything reminding them of their illness and not want to attend hospital appointments or talk about when they were ill. This anxiety normally subsides over time but, in a small number of cases, problems persist and require treatment.

The stress and anxiety be it short or long term, can contribute to **clinginess, temper tantrums, sleep disturbances, and regression to baby-like behaviour**. This can be especially marked in younger children who cannot tell you what the problem is in any other way.

Talking to your child

If your child became ill at an age when they remember their time in hospital, it can be helpful to talk about the experience with them. Some parents find this difficult because they themselves are very emotionally upset about their child's illness. Even so, it is often worthwhile to find a good time to talk things over. This gives them a chance to tell you whether they are troubled by memories of being in hospital and allows you to try to put their mind at rest about unnecessary concerns.

Some children may find it difficult to speak to their parents about their experience, but may find it beneficial to talk to others, or express themselves in other ways, such as art or play therapy. Some children may not want to talk about it at all. This is perfectly normal and they should not be forced to talk about it if they don't want to.

Creating a story or diary of your child's illness covering before, during, and after their stay in hospital, including pictures can sometimes help families process what has happened. This is something you can look at with your child if and when you are both ready.



Depending on the severity and type of illness, brain function may be affected and lead to difficulties in concentration and learning. Research shows that this often improves over time, but it may contribute to some behavioural change in the child in the short-term; for example sleep problems, tiredness/irritability and restlessness/over-activity.

Understandably some parents may find themselves giving in to their children much more than before the illness. This can make the child anxious and problems with behaviour or emotion can become worse. It helps to be as firm and consistent with your child as you were before. If fatigue is the cause of your child's irritability you can also look into ways of helping your child to rest. This could involve speaking to your child's teachers about a phased return to school, or encouraging a gradual return to sporting or social activities outside of school.

Fatigue and behavioural problems are often temporary, but can last for several weeks or months. They are quite common three months after coming home from hospital and normally improve over the year after the illness.

If you are finding these problems difficult to manage or you are concerned that there seems to be no improvement in your child's behaviour over time see 'How can I access further care?' on page 33.

My child has lost skills/has co-ordination problems

Some children may forget skills they have recently acquired. Toddlers who were speaking fluently before their illness may go back to baby talk, crawling instead of walking, or need nappies even though they were toilet trained before they went into hospital. Many children have subtle problems with balance or co-ordination. As well as this, children may have difficulties with concentration or memory, which can make returning to school more challenging.

It is important to talk to the paediatrician about these problems if you notice them before the 4-6 week review because they could be temporary or a sign of injury to the brain or inner ear damage¹². It is also important to make sure that your child has had a hearing test. See 'How can I access further care?' on page 33.



Loken's story



Loken fell ill with meningococcal septicaemia just a few weeks before his second birthday. He was treated in intensive care after developing a severe rash all over his body and was in an induced coma for six days.

Loken was unresponsive when he was finally woken up, but he became more aware of his surroundings on a daily basis, completing his recovery on a children's ward. Loken appears to have made a full recovery, but mum Andrea recalls that improvements were slow going at times:

We were in and out of hospital for the first few weeks because Loken's temperature would not go down. He got better and better every day since leaving hospital although he had to learn to walk and talk again and this took between two to three months. We feel so lucky that Loken is now fine apart from a few scars on his body where the disease struck, but we will remain vigilant for late onset issues that might become apparent as he grows and attends school.



Uncertainty over whether my baby has after effects

It can be hard to tell whether young babies have any long-term after effects at the time of discharge because they have not yet reached many of their developmental milestones. Generally, children who have been more unwell in hospital, for example with convulsions or coma are more likely to have after effects. Even children who do have prolonged seizures or other neurological complications can recover without after effects, but assessing children who have been seriously ill like this is especially important.



Tom's son Nicholas had meningitis at 17 days. Nicholas' development was a little delayed at first but by age two he was reaching all his developmental milestones.

If you are concerned that your child has been left with after effects, it can be useful to refer to a development checklist, which gives advice on what you can expect from your child's development from birth to five years old. A well-known checklist, the birth to five timeline, can be found on the NHS choices website¹³.

www.nhs.uk/tools/pages/birthtofive.aspx

Although all children are different, we know that there are certain ages when most children can perform a particular task. If your child is falling behind against milestones in the development checklist you should tell a health professional. Meningitis occurring at the time of rapid brain growth can potentially lead to damage to the brain. Although there are many reasons why some children develop some abilities later than others, late development in your child could indicate a brain injury from the meningitis. Whatever the reason for your child's delay, early treatment is the best way to help your child catch up. See 'How can I access further care?' on page 33.

If you have any concerns about your child after discharge from hospital you can discuss these with your GP or health visitor at any time.

It is a good idea to note down concerns and take these with you to the review with the paediatrician. It can also be helpful to keep a record of any ongoing concerns in your child's journal for at least a year after the illness. This may help you identify times when your child is at their best/worst and things that may contribute to this. It can also help you see some problems improving significantly over time.



Should I speak to my child's school or nursery about their illness?

Yes. It is common for children to experience fatigue, concentration and memory, co-ordination and behavioural problems after discharge which can make returning to school or nursery difficult.

Take this booklet and your child's journal when you meet with the teacher, so that they are aware of the sorts of problems that your child is likely to face.



For many children, going back into school and undertaking routine activities can be very helpful, provided of course that they are ready to meet the demands of school. Returning to school or college too early or too energetically may slow down recovery.

If you think that your child is not fully ready to return to school full-time, then we would suggest speaking to the class teacher and/or head teacher about them attending on a part-time basis initially.

Many families have found this helps their child make the transition back to school without putting too many demands on them.

The school may ask for a letter from the hospital to explain your child's illness. Your child's paediatrician can give you a letter for the school on discharge from hospital or at the 4-6 week review. It is always a good idea to make sure that your child's GP is aware of your child's illness (although the GP should have been informed already by the discharging paediatrician¹). The GP may need to provide a doctor's note to confirm the nature of your child's condition if your child needs time off school.

What late development after effects should I be aware of?

Most children and young people who go home from hospital without any obvious effects should not worry that new problems will develop after the illness, but some of the more subtle after effects of brain injury or damage to bones (in cases of septicaemia) may not be identifiable until years later.

Try not to expect problems if your child seems to have recovered without any effects on their learning or development. This should help your child develop their self-confidence uninhibited by negative expectations.

If some difficulties are identified by you or the teachers, it is possible that these will turn out to be minor and easily overcome with the right support. It is important that if any educational support is needed, that this is identified at an early stage to ensure your child receives the right help when they need it. Moving between schools can be a difficult time for children, and it's important to look out for any problems and ensure they are dealt with as they appear.

More information on how to deal with problems associated with your child's education is available [online](#).

www.meningitis.org/After-Effects-Children

www.meningitisnow.org/after-effects

Learning and behavioural problems

Some of the less obvious after effects of a brain injury, such as co-ordination, concentration, learning and memory difficulties, may not become apparent until your child reaches school age and is required to concentrate for longer periods of time.

The brain takes over 20 years to fully develop so some problems may not be noticeable until your child is older. The move from primary to secondary school can be particularly difficult. Following a complex timetable, meeting many new teachers, constantly moving around a larger school and remembering homework are just some of the situations that can be very difficult for a child who has memory or concentration difficulties. This can cause frustration and anxiety, and possibly lead to poor behaviour both at home and at school.

Although most children recover without lasting problems, there is a growing body of evidence that children who survive bacterial meningitis and meningococcal septicaemia are more likely to struggle at school in terms of both academic performance and behaviour compared to other children¹⁴⁻¹⁹. It is not always possible to be certain that such effects are a direct result of a child having had meningitis and septicaemia. However, bringing this evidence to the attention of your child's GP or teacher may help you gain access to specialist services and support that can further identify and ultimately help your child to manage the problem.

If you notice that your child is experiencing new or different problems it is really important to speak to their teachers and raise your concerns.

More information about brain injury and how to access care is available [online](#).

www.meningitis.org/After-Effects-Children

www.meningitisnow.org/after-effects

James' story



James was 4 when he became ill with meningococcal disease. His mum Sue initially thought he had the flu, but when she noticed the characteristic rash under his arm she became concerned that this was more serious. James was rushed to hospital. Thankfully he responded well to the antibiotics

and was sent home within five days with no apparent after effects.

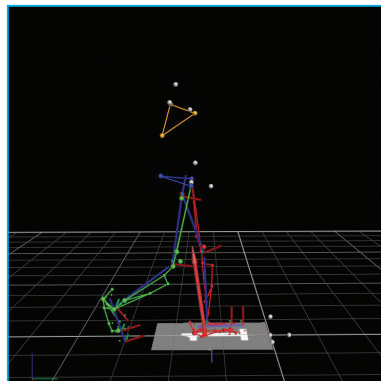
James was 7 when his Year 2 teacher noticed that he had a few problems with reading. At first they thought he was dyslexic, but after seeing a paediatrician, dyspraxia (associated with problems of perception, language and thought) was diagnosed. As a result, an occupational therapist visited the school to give him some techniques to overcome his difficulties. Sue, James' mum says:

James is now a typical 17 year old. Although he has had problems with formulating thoughts, he has managed to overcome this to some degree by 'mind mapping' (making diagrams to visually outline information). It has also taken him a long time to learn organisational skills although he is very good now. He is currently studying Biology, Physics and Psychology A-levels and is on target to receive good grades. We consider ourselves to be incredibly lucky in so many ways.

Growth plate damage (septicaemia only)

It is a good idea for children who had skin grafting or have significant scarring over their joints after septicaemia to have their growth and limb length monitored by a paediatrician or GP. This is because there is a risk that the end parts of the bones which control growth could have been damaged whilst they were ill²⁰. It is also a good idea to look out for loss of wrist and forearm movement if these have been affected by skin damage²¹.

Reproduced with permission from the Ryegate Centre run by Sheffield Children's NHS Foundation Trust



A child having his walking pattern measured. This type of analysis is used to help plan and monitor improvement after surgery for bone growth deformity.

More information about growth plate damage and how to access care is available [online](#).

www.meningitis.org/After-Effects-Children

www.meningitisnow.org/factsheets

What about my health as a parent?

Seeing your child or loved one seriously ill in hospital and being powerless to help them can be an extremely stressful and traumatic experience and can affect your own well-being. You may find that you briefly re-experience aspects of your child's time in hospital. At times, you may feel as though the event is recurring, have nightmares or experience vivid intrusive images/sounds/smells from the event, all of which can be very distressing. Equally, you may find yourself constantly questioning why this has happened and how it could have been prevented, or you may try and push the event out of your mind altogether and avoid talking or thinking about it at all.

It is perfectly normal to have these feelings initially but, if they are prolonged, they could become problematic. If you identify with the feelings described above, find that you are having problems with irritability, poor concentration and sleep problems, or find yourself withdrawing from family or friends for a prolonged period it is a good idea to talk these through with a health professional. If these symptoms continue for over one month then you may be suffering from post-traumatic stress disorder (PTSD). Treatments are available to help. Your GP will be able to assess your condition and co-ordinate your treatment if required²².

Symptoms of PTSD can be delayed²³, so if you start to experience symptoms like this after the event, and you wish to get help, then discuss this with your GP.

It is common to neglect your own needs when caring for a child you love, but to be at your best you need to look after yourself too.

Creating a personal story or diary of your child's illness can sometimes help process what has happened, and you can look at it with your child if and when you are both ready.



The wider impact on family life

Having a child with meningitis or septicaemia can have a major impact on family life; the recovery process can take time for everyone including grandparents and the wider family. Understandably, parents may take longer to adjust after such a traumatic experience, even if their child makes a full recovery.

It is important that all the family receive care and support to meet their needs. Brothers and sisters, particularly young children, will need extra attention and understanding because they can feel anxious and isolated. Parents often feel guilty about dividing their time and attention between their children.

Meningitis Research Foundation free helpline 080 8800 3344

Meningitis Now free helpline 0808 80 10 388



Edward with his twin brother William. Edward had meningococcal septicaemia at age 7.

Serious and long-term after effects

Although the majority of children who survive meningitis and septicaemia recover without serious after effects, some children may recover with at least one of the effects listed below. Many of these after effects are long-term, but treatment and support may improve or help manage the problem:

- Hearing loss and tinnitus
- Balance problems
- Hydrocephalus (water on the brain)
- Sight loss
- Epilepsy
- Problems with movement and co-ordination (ranging from muscle weakness to paralysis)
- Behavioural/emotional problems
- Memory/concentration problems
- Learning problems (ranging from mild difficulties to severe disability)
- Speech and language problems

Some after effects only affect children who have been ill with septicaemia. These are:

- Skin and muscle damage
- Amputations including loss of fingers, toes, and limbs
- Bone growth problems
- Organ damage (such as kidney failure)

It will usually be apparent if your child has any serious or long-term after effects before leaving hospital. In such cases the paediatrician or other members of the team treating your child should discuss this with you before discharge and refer your child to other specialists for follow up.

Hearing loss is the most common long-term after effect of meningitis. Hearing difficulties can range from a mild degree of hearing loss through to profound deafness in both ears. Damage to the inner ear can also cause **balance problems** and **tinnitus** (ringing in the ears)²⁴⁻²⁶. Depending on the level of hearing loss, decisions about hearing aids or cochlear implants and ways of communicating with your child will need to be made. A cochlear implant is a surgically inserted device that provides a sense of sound to someone who is profoundly deaf or severely hard of hearing. If cochlear implantation is an option, the decision and referral to an ENT specialist will need to be prompt. Your local education and audiology services can help and support you and provide the information you need.

Hydrocephalus (water on the brain) is a rare after effect of meningitis. It happens when the flow of CSF, which circulates around the brain and spinal cord, becomes restricted and starts to build up, putting pressure on the brain. It may be a short-lived complication while the child has meningitis, but can sometimes persist after recovery. If the build up of fluid is temporary, then it may be treated by monitoring and occasional drainage via lumbar puncture. If it is permanent, a shunt device will need to be surgically inserted.

Nervous system injury, particularly damage to the brain, results in other after effects of meningitis. This can cause severe brain damage or more subtle changes to the brain which can take months or even years to become apparent. An injury to the brain that happens after birth is called an acquired brain injury (ABI). Both meningitis and septicaemia can cause ABI but this is usually associated with meningitis in particular.

Brain injury after meningitis can result in a wide variety of long-term problems such as **sight loss, epilepsy, problems with movement and co-ordination** (ranging from paralysis of limbs to muscle weakness), **learning problems** (ranging from mild specific problems to severe disability) and **speech and language problems**. Severe brain damage following meningitis is not common and is usually obvious within a few days of becoming ill. If it is clear that your child has some form of brain damage after meningitis, hospital staff should explain what the outcome may be and co-ordinate the necessary treatment and support before your child is discharged from hospital.

Other effects of brain injury after meningitis and septicaemia include specific learning difficulties, **behavioural, emotional, concentration and memory problems**. These problems may not be noticed until children become old enough to attend school and are required to concentrate for longer periods of time.

In very young babies, 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. See page 18.

*More in depth information about long-term after effects from meningitis and septicaemia is available in **online** factsheets. If your child has any known after effects before the review with the paediatrician, it may be helpful for you to download and read through the relevant factsheets before attending this appointment.*

www.meningitis.org/After-Effects-Children

www.meningitisnow.org/factsheets

Lauren's story



Lauren contracted group B streptococcal meningitis when she was six weeks old.

When recovering from meningitis Lauren's parents were told that she may never walk or talk - hard to believe when you see her now.

Her passion for cycling has seen her win two gold medals at the British Para-Cycling National Championships! Lauren is still enjoying cycling and actively competing at a national level, striving to hold onto her titles.

Looking at Lauren people don't see the damage that meningitis has caused such as; hearing loss, cerebral palsy (causing weakness in her left arm and leg), and speech and memory problems.

Lauren struggled at school; her family raised concerns, but were told she was just 'slow'. A computerised tomography (CT) scan showed damage to her brain and eventually she got one-to-one support at school which increased her learning enormously.

Lisajayne, Lauren's mum, says:

Lauren went through so much as a baby, I just want her to be able to cope with the changes ahead. Victims of meningitis shouldn't face barriers; children should get the education and support they deserve.

After effects of septicaemia

Large numbers of bacteria in the blood stream release toxins which cause blood vessels to become leaky. Bodily damage from septicaemia is caused by reduced blood supply and increased blood clotting in various parts of the body. If the blood supply is cut off for a prolonged period it can cause permanent damage to skin, muscle, bones and organs.

Skin and muscle damage may need skin grafts to improve the appearance and restore the function of injured areas. More severe cases of septicaemia may result in the loss of fingers and toes, or if larger areas of the body are affected, surgical amputation of limbs or parts of limbs may be necessary.

Septicaemia can cause **bone growth problems** if blood supply to the growth plates (points within the bones which control growth) is cut off during the acute illness. Although uncommon, these problems can result in uneven or stunted growth of limbs as the child develops and are more likely if your child has skin scarring around their joints. Repeated surgery may be needed to correct this problem.

Reduced blood circulation can cause vital organs to fail. Such serious cases are treated in intensive care, where machines take over the function of these organs. Usually the organs recover completely, but in rare cases septicaemia can cause permanent **damage to organs**. Depending on the effects of the damage caused, ongoing treatment with frequent hospital visits can be expected.

*More in depth information about long-term after effects is available **online**. If your child has any known after effects it may be helpful for you to download and read the relevant factsheets before attending this appointment.*

www.meningitis.org/After-Effects-Children

www.meningitisnow.org/factsheets

Aaron's story

With kind permission of New Forest National Park Authority



Aaron took a keen interest in extreme sports as a teenager such as rollerblading, skateboarding and BMX riding, as well as playing basketball for his school team.

At 15 years of age Aaron contracted meningococcal septicaemia. This came from seemingly harmless flu-like symptoms, which 12 hours later

saw him on a life support machine. Aaron's life had turned upside down and after being in a controlled coma for two weeks, both his legs and most of his fingers had to be amputated.

Although Aaron had to stay in hospital for a year recovering and rehabilitating, he adapted quickly to the life changing situation thrown at him. Eight months after being discharged, he enrolled at college in an attempt to gain A-level qualifications as his life returned to some kind of normality.

Since then he has returned to his love of sports and taken up wheelchair racing which saw him finishing as the fourth highest placed UK male in the **2009 London Marathon**. He has also become an established member of the **GB wheelchair rugby squad** taking part in the **London 2012 Paralympic Games**. Aaron is happily married to Vicki and has two daughters.

How can I access further care?

How you go about accessing further care for your child will depend on whether your child is still an outpatient of the hospital that treated their meningitis or septicaemia:

- If your child is still an outpatient, then you can discuss any concerns that you or your child has with the hospital paediatrician who can refer you to an appropriate specialist or service if this is required
- If your child is no longer being seen as an outpatient, then you can go to your GP or health visitor for advice and/or referral back into 'the system' if this is necessary. It is important to tell your health visitor or GP that your child has had meningitis and it could be helpful to show them this booklet and your child's journal.

If you are concerned about your own health following your child's illness and are experiencing symptoms similar to those described in 'What about my health as a parent?', make an appointment with your GP to discuss your concerns.

Where can I go for support?

Meningitis Research Foundation

We know that recovering from meningitis and septicaemia isn't easy. Facing the future can be harder still. With nearly 30 years experience of supporting people affected we are here to help.



Free membership – There's no need to feel alone in coping with these diseases. We understand what you're going through and joining our 17,500-strong membership will enable you to stay up-to-date with the latest developments, learn about our work and meet people with similar experiences at Member Days and events. You can take part in research or attend a Discovery Day to learn about our pioneering research from the scientists themselves.

In-depth support and disease information – We provide one-to-one support, and with the help of experts, we find answers to the questions you need answered, enabling you to make more informed decisions about your child's care and feel reassured about what the future may hold.

Befriending – Support and understanding from someone who's been there. We match people to trained befrienders with a similar personal experience.

Home visits – We come to you to talk through questions and concerns.

Pushing the Boundaries information and disability information – Join us for an inspirational and fun day for the whole family. Let the kids play games whilst you learn about the disease and how to manage after effects from expert clinicians, and share stories and understanding with other families with similar experience.

Our vision is a world free from meningitis and septicaemia. We have invested over £19 million in research, leading to many advances in the detection, prevention and treatment of these diseases.

For information and support:

-  **Free helpline 080 8800 3344**
-  **helpline@meningitis.org**
-  **facebook.com/meningitisresearch**
-  **@M_R_F**
-  **www.meningitis.org**

Meningitis Now

Meningitis Now is a UK meningitis charity. We are 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 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.

We can:

- Listen; and answer your questions enabling you to make informed choices about care and support
- 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
- Bring people together at our support days, to share experiences, exchange information and provide reassurance following meningitis

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



Free helpline 0808 80 10 388 (UK)



www.MeningitisNow.org



info@meningitisnow.org



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www.healthunlocked.com/meningitisnow

Acknowledgements

We are very grateful to the following experts whose feedback and support has been invaluable:

Dr Lorraine Als, Research Psychologist; **Helen Campbell**, Senior Clinical Scientist, Public Health England (PHE); **Miss Naomi Davis**, Consultant in Paediatric Orthopaedic Surgery; **Dr Liam Dorris**, Consultant Paediatric Neuropsychologist; **Prof Elena Garralda**, Child and Adolescent Psychiatry; **Dr Scott Hackett**, Consultant Paediatrician; **Vicki Kirwin**, Audiology Specialist; **Dr Rachel Kneen**, Consultant Paediatric Neurologist; **Prof Simon Kroll**, Paediatrics and Molecular Diseases; **Sheila McQueen**, Academic Head of Nursing Science; **Mr Fergal Monsell**, Consultant Paediatric Orthopaedic Surgeon; **Dr Simon Nadel**, Consultant in Paediatric Intensive Care; **Dr Nelly Ninis**, Consultant Paediatrician; **Dr Ifeanyichukwu Okike**, Consultant; **Dr Mary Ramsay**, Head of Immunisation, PHE; **Dr Andrew Riordan**, Consultant in Paediatric Infectious Diseases and Immunology; **Dr Andrew Winrow**, Consultant Paediatrician.

Our special thanks to the representatives of the Royal Colleges, who provided their time, expertise and encouragement throughout:

Dr Alistair Thomson

Dr Janice Allister, Child Health Representative, Royal College of General Practitioners

Fiona Smith, Adviser in Children and Young People's Nursing, Royal College of Nursing

Finally we wish to thank all of our wonderful families who are always so generous and willing to give their time, and share their experiences.

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Notes



Meningitis Research Foundation
Newminster House
Baldwin Street
Bristol
BS1 1LT

Tel: 0333 405 6262
Free helpline: 080 8800 3344
Email: info@meningitis.org



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Meningitis Now
Fern House
Bath Road
Stroud
Gloucestershire
GL5 3TJ

Tel: 01453 768000
Free helpline: 0808 80 10 388 (UK)
Email: info@meningitisnow.org



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