

Learning and developmental difficulties - meningitis and acquired brain injury

This fact sheet provides information about the learning and developmental difficulties that children and young people can experience following meningitis or meningococcal septicaemia.

More information about meningitis 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**.

What happens after meningitis or meningococcal septicaemia?

Meningitis and meningococcal septicaemia are serious diseases that can affect anyone at any time. Although most people will make a good recovery, some will be left with severe disabilities and others with less obvious, but still life-changing, after-effects.

Meningitis is inflammation of the membranes that surround and protect the brain and spinal cord. Some bacteria that cause meningitis can also cause septicaemia**. Both meningitis and septicaemia can cause acquired brain injury (ABI). This is an injury to the brain that has happened after birth.

The brain takes over 20 years to fully develop. If a child or young adult has meningitis*, the development of the brain can be affected. The changes may not be apparent immediately after the illness; it may take months or even years before any changes are noticed.

meningitis* refers to meningitis and meningococcal septicaemia.

septicaemia** many medical experts now use the term sepsis instead of septicaemia.

Key points

- These after-effects may not be apparent until several months or even years after the illness
- Continued monitoring and follow-up care are essential
- Remember that you know your child better than anyone else

Our commissioned research project (MOSAIC) confirms that meningococcal disease has a lifelong impact, leaving a significant number of survivors with reduced IQ and difficulties with memory, concentration and planning. The research has also shown that survivors are significantly more likely to need additional educational support or experience mental health disorders and physical disability.

Most children make a good physical recovery following meningitis, and many of these will have no further problems. However, it is important that all children are assessed regularly so that those who need educational or other support are recognised at an early stage.

On the next page we have listed some of the difficulties children can encounter after meningitis and ABI. If you have noticed that your child is experiencing any of these difficulties, it is important to speak to their teacher and explain that your child has had meningitis, even if it was several years ago. If your child hasn't started school, you can talk to your health visitor or GP.

Remember that you know your child better than anyone else.

Attention and concentration

It may be difficult to concentrate and stay focussed in a noisy classroom, or to cope with more than one task at a time.

Memory

Difficulties with aspects of memory can have an impact at school or at home. This can make learning and retaining information very difficult.

Perception

Difficulties with perception can affect spatial awareness, number and letter recognition, reading from left to right and copying from the board.

Executive skills

It may be difficult to organise and plan activities, such as homework, to be aware of consequences or to self-monitor behaviour. These difficulties can become more apparent once a child starts secondary school.

Fatigue

This can continue long after the brain injury has occurred. Children can become increasingly tired as the week progresses or become suddenly tired, for instance when trying to concentrate on school work. This can adversely affect many areas of their life, including friendships and after-school activities, if they are too tired to socialise after school.

Behaviour

Changes in behaviour are difficult for families, friends and schools to cope with and they can be a significant barrier to developing relationships at home and school. A child may be very withdrawn or may be impulsive, aggressive and lack inhibition.

Social skills

Social expectations can be hard to understand and children may have difficulty making friends, making eye contact, understanding humour or having a conversation.

Communication

Difficulties with speaking and understanding language can occur following a brain injury. This can make it hard for a child to hold a conversation, follow verbal instructions or express their own worries and concerns.

Emotional difficulties

Loss of confidence, mood swings and depression may occur. Anxiety about the future can also lead to frustration and anger. Children may be bullied because they are seen as different by others.

Physical difficulties

Some children may have physical difficulties that have an impact on learning and social development. These include epilepsy, muscle weakness, hearing loss, visual difficulties and limb loss. Transport to and from school, movement around the school, playground activities and PE lessons all need to be considered.

In some cases, these physical difficulties have to take priority when planning care and education. However, it is important to remember that a child with physical difficulties may also be experiencing some of the other difficulties already listed and these should not be overlooked.

A lack of information about ABI, for both parents and those working with children, can make it difficult to get the right help and support. It can also lead to children with ABI being labelled as naughty when in fact their behaviour is sometimes beyond their control.

Good rehabilitation, help and support at school are vital to ensure that children are reaching their maximum potential.

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

Further detailed fact sheets are also available covering the following topics:

- Structure and function of the brain
- Physical effects of ABI
- Sensory effects of ABI
- Learning and cognitive effects of ABI
- Behavioural and emotional effects of ABI
- Speech, language and communication difficulties after ABI

Download at www.MeningitisNow.org/recovery

Getting help

Whatever your concerns following meningitis, you can talk to our experienced staff who will explain what help we can offer. Our Community Support Officers (CSOs) are based across the UK; offering a listening ear and wealth of knowledge and experience – either by phone, email or a home visit.

We work with a range of specialist organisations to provide emotional and practical support whenever it is needed, for as long as it is needed. We never want anyone to suffer alone.

If you are concerned about your child's educational needs, speak to your child's teachers and/or to the school's special educational needs co-ordinator (SENCO) and let them know your concerns. Tell them that your child has had meningitis, no matter how long ago.

Children with special educational needs and/or disability (SEND) will need extra support to reach their full potential. The SEND Code of Practice gives guidance to schools to help them identify, assess and provide support for children with SEND. It sets out procedures schools should follow to meet the needs of children. There is a guide for parents and carers which explains this code and how to get help for a child.

If you are not getting help or support from your child's school please contact our helpline. Our community staff can provide individual information and support and may be able to assist you in getting the help you need.

Further information

Special Educational Needs and Disability (SEND)

England

- **SEND Code of Practice**
www.gov.uk/government/publications/send-code-of-practice-0-to-25
- **SEND guide for parents and carers**
www.gov.uk/government/publications/send-guide-for-parents-and-carers

Northern Ireland

- **The SEN Code of Practice is currently being updated. A draft version of the new code can be seen here:**
www.education-ni.gov.uk/consultations/consultation-draft-sen-code-practice

- **Special Educational Needs Advice Centre (SENAC)**
www.senac.co.uk
A regional charity that offers free, independent advice and advocacy on the special education system in Northern Ireland.

Scotland

- **Schools – additional support for learning**
<https://www.gov.scot/policies/schools/additional-support-for-learning/>
- **Information for parents**
<https://enquire.org.uk/>

Wales

- **Additional learning needs information**
<https://gov.wales/additional-learning-needs-code>

UK organisations

- **Information, Advice and Support Services Network**
<http://cyp.iassnetwork.org.uk/>
IAS Services have a duty to provide information, advice and support to disabled children and young people, and those with SEN, and their parents. There should be an IAS Service in every local authority.
- **Independent Parental Special Education Advice (IPSEA)**
www.ipsea.org.uk
A national charity providing free legally-based advice to families who have children with special educational needs.
- **SOS SEN**
www.sossen.org.uk
A free, friendly, confidential telephone helpline for parents and others seeking information and advice on special educational needs.
- **Brain Injury Hub**
www.thechildrenstrust.org.uk/brain-injury-information
An excellent information resource and forum covering all aspects of childhood brain injury.
- **Child Brain Injury Trust**
www.childbraininjurytrust.org.uk/
A charity providing support, information and training about childhood acquired brain injury.

- **Headway**
www.headway.org.uk
A charity providing information, support and services to people with a brain injury, their families and carers.
- **Advisory Centre for Education**
www.ace-ed.org.uk
A national charity that provides advice and information to parents and carers on a wide range of school-based issues including special educational needs .
- **Contact a family**
<https://contact.org.uk/>
UK-wide charity providing advice, information and support for families with disabled children.

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

Meningitis Now

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



Meningitis Helpline
0808 80 10 388 (UK)

mosaic

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 (MenB) three years previously, when they were between the age of one month and 13 years. The other children (controls) had not suffered MenB. 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 MenB.

Results

Cognitive skills

Children and young people who have survived MenB 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 difficulties with organisation and planning

Physical

The following physical limitations and after-effects were reported in the survivors of MenB:

- 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 difficulties – five times more likely compared to controls

Mental health

One in five children and young people who have survived MenB have anxiety and behavioural disorders.

Summary

More than a third of children who have survived MenB experience difficulties with cognitive, physical and/or psychological function.

How will the results be used?

- the results of this unique study have already been presented, as evidence of the burden of MenB, 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.

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