

Education - Your child's rights

Starting school or returning to school after meningitis or septicaemia is a big step in your child's recovery and rehabilitation. For many it means getting back to 'normal', but it can also bring its own challenges.

Some children will be back to their normal activities within a couple of weeks. However it is common for children to have problems with concentration, behaviour, co-ordination, fatigue and headaches for some weeks or months after they are discharged from hospital. Some children benefit from a gradual return; helping them to take the time to recover and adjust to the school day again.

It is a good idea to speak to someone at your child's school about their return following illness. Providing a copy of 'Your guide' for the teachers to read so that they are aware of the sorts of problems that your child might face can be helpful. You can also use your child's Journal to share information with school about your family's experience and to record your child's return to school. Keeping a record may help you to see the progress your child makes over time or help you to identify any problems or difficulties they encounter.

Some children can be left with long-term physical, emotional, and behavioural problems after meningitis and septicaemia. If your child has been left with after effects from their illness, they may have difficulties with certain aspects of school and need additional support, or a special school may be an option for some children.

A special school may offer smaller classes, and teachers who have specialist knowledge about teaching children with special educational needs (SEN). Therapy can be incorporated into the school day, and children will follow a programme of study that has been planned with their needs in mind. A child will only be offered a place in a Local Authority special school if they have been formally assessed and issued with a statement of Special Educational Needs.

Sometimes problems are not immediately obvious; after effects, such as learning and behavioural problems may only become apparent over time. The brain takes over 20 years to fully develop, so some problems with concentration, memory and problem solving may not be noticeable until your child is older and is required to complete more complex tasks and pay attention for longer periods of time at school.

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 children¹⁻⁶. Although it is not always possible to be certain that such effects are a direct result of a child having had meningitis and septicaemia, speaking to your child's teacher may help you get support and ultimately help your child to manage the problem.

If you have concerns that your child is struggling at school following meningitis (regardless of whether this is immediately after the illness or years later) then it is important that you know your rights and how to access help.

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Numbers within the text that appear as subscripts like this ¹ correspond with numbered references listed at the end of this fact sheet.

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A right to education

Everyone has the right to education and Local Authorities (LAs) have a statutory duty to ensure that education is available for all children of compulsory school age in their area, appropriate to their age, abilities, aptitudes and any special educational needs they may have. Local Authorities also have a duty to give parents in the area the opportunity to express a preference as to which school they wish their child to attend.

The key pieces of legislation are the Education Act 1996 and the Special Educational Needs (SEN) Code of Practice (2001), effective from 1st January 2002. The SEN Code of Practice is an important document to refer to, which is easy to read and contains law as well as guidance on how and when a child will need additional support. It is available from <http://www.education.gov.uk/aboutdfe/statutory/g00213170/special-educational-needs-code-of-practice>

Education settings, schools, LAs, and health and social services should always consider what the SEN code of practice says when deciding how to help children with SEN. Changes to the SEN framework are currently underway and a new SEN code of practice is expected to be issued in September 2014 to reflect these changes.

Special Educational Needs

The nature of these diseases means that children can be left with physical, emotional, and behavioural problems. Sometimes these are immediately obvious, such as profound hearing loss and limb loss, but for others, problems such as concentration, memory loss can be due to an acquired brain injury (ABI), which can become apparent over time; either way they can result in a child having SEN.

In a typical classroom, children make progress at different rates and have different ways in which they learn best. Teachers take account of this when planning lessons and use different approaches and resources to help meet the needs of individual children or a group of children. This is called “differentiating the curriculum” and is a normal part of the teacher’s role.

If your child is having difficulties in a particular area they may be given extra help or different lessons, but this does not necessarily mean they have SEN.

Some children may need more help. For example, they may have difficulty with reading or writing, they may need extra support with spoken communication or help with developing social or physical skills. A child who needs a lot of extra help has SEN.

The law defines children with SEN as children who have considerably greater difficulty in learning than others of the same age, or who cannot use the educational facilities other children use because of a disability. The law also indicates that a child only has special educational needs if their learning difficulty calls for special educational provision to be made. Children with SEN may need help with:

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- Physical or sensory difficulties
 - o mobility problems - either due to acquired brain injury (ABI) or because of tissue damage, limb loss, hearing loss and sight loss which can all be after effects of meningitis or septicaemia
- Speech and language difficulties
 - o problems can be due to hearing loss or ABI as a result of meningitis and septicaemia
- Thinking and understanding, emotional and behavioural difficulties or how to relate to and behave with other people
 - o These effects can be as a result of ABI after meningitis and septicaemia. They may be apparent as soon as your child leaves hospital, but can be late developing.

More information about the after effects of meningitis and septicaemia is available online from www.MeningitisNow.org/recovery or www.meningitis.org/recovery .If children are returning to school or preparing to start school with SEN, many considerations will need to be taken into account, such as, transport, movement around the school, classroom environment, playground and PE activities, and medication/medical support.

Involve the school at the earliest opportunity, Schools are required by law to have a Special Educational Needs Co-ordinator (SENCO). They are there to help school staff understand and help with any difficulties your child may have. Speak to the SENCO at your child’s school to ensure that they fully understand your child’s difficulties and needs. Depending on the level of your child’s needs, experts within the field, such as an occupational therapist, may need to help the school plan for any changes or adaptations to be made, ensuring that your child has the best opportunity to learn. If your child hasn’t reached school age yet and you have concerns about their development or behaviour, you can speak to your child’s doctor or health visitor who will advise you on what to do next.

If your child is at school and has not been identified as having special educational needs but you are concerned, arrange an appointment to speak to your child’s teacher, SENCO, or head teacher. It’s a good idea to write a list of the problems, including your child’s behaviour at home, if this worries you. Ask whether the teacher shares your concerns and what the school can do to help. Agree a date for a future meeting to discuss whether things have changed.

It is best to try and work with your child’s teachers to help resolve problems that your child is experiencing. The closer you work with the teachers, the more successful any interventions are likely to be for your child. If you feel the teacher or school aren’t listening or providing the right support you can contact your local Parent Partnership Service (PPS). As a statutory service, required by law, it is expected to be impartial, despite being funded by the Local Authority.

To find your local PPS just follow this link from the ‘National Parent Partnership Network’ website: www.parentpartnership.org.uk/find-your-pps

You can also contact the SEN National Advice Service, provided by the charity Contact a Family, on 0808 808 3555 (option 1) if you have concerns about your child’s education or just need more information.

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Additional support in school

If your child needs extra support this would usually start with 'School Action' which could include, individual or small group support from the class teacher and/or teaching assistant, a different way of teaching things, some help from an extra adult, or use of special equipment such as a computer. In nursery this help is called Early Years Action.

The school must tell you when they first start giving your child extra help because they have SEN.

Your child's progress should be recorded, in an Individual Education Plan (IEP). This document lists three or four short term targets, the help which will be given, and how success will be measured.

If your child needs more help than they can receive on School Action, the school may increase the level of support and call in professionals from outside the school, such as an educational psychologist, speech and language therapist or occupational therapist. This is called 'School Action Plus'. The school will then develop a new IEP based on the advice they receive from these professionals. The IEP will be reviewed by the school at least twice a year. You and your child should be included in any discussions or reviews about the IEP.

Not all schools will write an IEP, but they should always be able to tell you exactly how they are helping your child, what progress they are making and should also explain to you why they have not written an IEP.

Statement of Special Educational Needs

Most children with SEN do not require a statement of special educational needs. They will often have all their needs met in school via school action or school action plus. If the school is unable to provide all the help your child needs, or you disagree with the way your child is being helped, it is important that you talk to the SENCO about your concerns. If this does not resolve the problem you can ask the LA to carry out an assessment of your child's needs. This is called a statutory assessment of Special Educational Needs. The aim of creating a statement of Special Educational Needs is to set out what your child's needs are, the ways in which those needs are to be met, and in which school they should be met.

This statement is in part legally binding.

Either a parent or the school can request a statutory assessment, but it helps if you can do it yourself so you can be certain of all the timings. You should always ask in writing and keep a copy of the letter and the date it was sent. A model letter requesting an assessment is available from:

<http://www.ipsea.org.uk/What-you-need-to-know/SEN/Statutory-assessment.aspx>

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An outline of the SEN statement of process:

- There may be concerns that the school a child attends is not able to meet the additional needs they have following their illness. These concerns may come from the parents, the child's school or another professional working with the child
- Once the referral has been received, the LA has 6 weeks to decide whether they will undertake a statutory assessment
- If the LA decides not to undertake a statutory assessment, parents have two months from the date of the letter notifying them of this to appeal to the special educational needs and disability tribunal
- If approved, the local authority will ask for information about the child's needs from the parents, teachers, educational psychologists, doctors and any other relevant professionals such as physiotherapists. From the date that the assessment begins, the LA has 10 weeks to complete the assessment and decide whether they will issue a statement of SEN
- If the LA decides that a child does not need a statement, they must notify the parents and the school and give reasons for their decision. Parents have 2 months from the date of this letter to appeal against this decision
- If a child needs a statement, a 'proposed statement' is written. It's a bit like a first draft
- Then a final statement is written up
- The statement is put into practice in school
- The statement is reviewed every year or more frequently if necessary

If you are going through the process of requesting a statutory assessment of SEN for your child, there are organisations that provide specialist knowledge and support. See, 'Sources of information'.

Sources of information

The following links provide detailed information and practical help about the Statement process, including set times scales and appealing against a decision:

GOV.UK – Government services and information

www.gov.uk/children-with-special-educational-needs/overview

Contact a Family – A national charity that exists to support the families of disabled children whatever their condition or disability.

www.cafamily.org.uk/advice-and-support/sen-national-advice-service/more-on-the-statement-of-special-educational-needs/

IPSEA – A national charity providing free legally based advice to families who have children with special educational needs.

www.ipsea.org.uk/What-you-need-to-know/SEN/A-Statement-of-Special-Educational-Needs.aspx

Mencap – The leading UK charity for people with a learning disability

www.mencap.org.uk/sites/default/files/documents/2009-12/2008.292%20Understanding%20statements%20and%20statutory%20assessments.pdf

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