

Epilepsy in schools

Initials and their meanings

- LA: local authority
- CCG: clinical commissioning group
- SEN: special educational needs
- SEND: special educational need and disability
- IHP: Individual healthcare plan
- EHCA: education, health and care assessment
- EHCP: education, health and care plan

When your child is diagnosed with epilepsy, education is likely to be one of your first concerns. Many children, especially once their epilepsy is controlled by medicine, are unlikely to need any extra support. But some children will continue to have seizures and need medical or other support. Making sure the school knows about your child's epilepsy will give them the best chance of getting the learning, social and health support they need.

This information covers the ways in which the school should be supporting your child, and the laws behind that.

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- **My child has just been diagnosed with epilepsy. Should I tell the school?**

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- **The equality laws**
- **Extra information about the law in Scotland, Wales and Northern Ireland**

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LAWS

Which laws support my child with getting the best care in school?

- **What do local authorities have to do for children with medical conditions?**
- **What do local authorities have to do for children with special educational needs?**
- **The equality laws**
- **Extra information about laws in Northern Ireland, Scotland and Wales**

This information is for people living in England. It covers local authority schools, academies, private schools and free schools.

What do local authorities have to do for children with medical conditions?

If your child has a medical condition the school has to put things in place to support them. They have to do this with whether or not your child has special educational needs. This is written in the Children and Families Act 2014. There is guidance to support this requirement. It explains in more detail what your local authority and school should do.

Under the Act the school should provide the same opportunities for your child as any other child in the school. Here are the things a school should have in place for children with epilepsy:

- A plan to ensure all staff and children have an understanding of epilepsy
- If needed, a child's epilepsy medicine in school and staff trained in how to give it
- A clear understanding of what an emergency situation would be and how to respond to it
- Individual healthcare plans including who will be responsible for what and when. This information should be collected by talking to the child, parents and healthcare professionals. And it should be reviewed on a regular basis

What do local authorities and schools have to do for children with special educational needs (SEN)?¹

The school has a duty to support your child with any special educational needs. The law is in Part 3 of the Children and Families Act. The updates and details are in the special educational needs and disability code of practice: 0 to 25 years January 2015². The local authorities, school governing bodies, colleges, and a range of other bodies must 'have regard to it'. This means they must consider what the code says, and have very good reasons for not following the guidance.³

This is what the local authority should do for children with special educational needs:

- Consult with everyone involved
- Find out what the need is and put resources in place
- Make sure there are enough resources and check this regularly

¹ ChildrenAndFamiliesActBrief.pdf. Available at: <http://www.councilfordisabledchildren.org.uk/media/554523/ChildrenAndFamiliesActBrief.pdf> [Accessed April 19, 2016]p4

² SEND_Code_of_Practice_January_2015.pdf. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND_Code_of_Practice_January_2015.pdf [Accessed April 19, 2016].

³ ChildrenAndFamiliesActBrief.pdf. Available at: <http://www.councilfordisabledchildren.org.uk/media/554523/ChildrenAndFamiliesActBrief.pdf> [Accessed April 19, 2016]

- Work with the relevant healthcare organisations for joined-up provision
- Make sure their plans and resources are available for the public. This information is called the Local Offer
- Enable children to stay in mainstream education wherever possible
- Provide assessments and plans for children needing educational health and care assessments (EHCA)

More information on education, health and care assessments (EHCA) and plans (EHCP)

The equality laws

In the UK most children diagnosed with epilepsy will be covered by the Equality Act 2010 in England, Scotland and Wales. In Northern Ireland it's the Disability Discrimination Act.⁴ This means that they must not be discriminated against. This includes making sure they have the same access to school activities as any other pupil, wherever possible.

Extra information on epilepsy in schools in Northern Ireland

Local authority and schools policies for children with medical conditions and children with special educational needs in Northern Ireland

For people living in Northern Ireland the policies for supporting children with medical conditions are similar to those for England but the laws behind them have different names.⁵

[Supporting pupils with medication needs 2008](#) ⁶

This policy describes the appropriate care and support for children with medical needs in school.

One difference is that it says there is some insurance cover for staff administering ⁶emergency medicine.

If your child has special educational needs which are not being met you can ask for a statutory assessment. This needs to be in writing, to the Special Educational Needs section of your local Education and Library board.

⁴ Equality_Act_Advice_Final.pdf. Available at:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/315587/Equality_Act_Advice_Final.pdf [Accessed April 12, 2016].

⁵ Legal-Situation-in-Schools.pdf. Available at: <http://medicalconditionsatschool.org.uk/documents/Legal-Situation-in-Schools.pdf> [Accessed April 19, 2016]

⁶ Supporting pupils with medication needs | DE. Available at:

<https://www.deni.gov.uk/publications/supportingpupils-medication-needs> [Accessed April 19, 2016].

The Special Educational Needs and Disability (Northern Ireland) Order 2005 (SENDO)⁷

This improved the existing rights of children with special educational needs under the Education (NI) Order 1996 to be educated in a mainstream school. It also introduced disability discrimination legislation to cover schools, further and higher education and general qualification bodies.⁸

[The Dispute avoidance and resolution service \(DARS\)](#)⁹ is an independent service which can help if you have problems communicating with the school or local authority. You would need to contact your [local board](#).

Website: education-support.org.uk/parents/special-education/contact-details/

For a range of government information on special educational needs

Website: nidirect.gov.uk/information-and-services/schools-learning-and-development/specialeducational-needs

Extra information on epilepsy in schools in Scotland

Local authority and schools policies for children with medical conditions and children with special educational needs in Scotland

For people living in Scotland the policies for supporting children with medical conditions are similar to those for England but the laws behind them have different names.¹⁰

The Education (Scotland) Act 2016¹¹

This will improve rights for children and offer a support service. It should start happening in 2017.

[The Children and Young Person \(Scotland\) Bill 2014](#) says that the local authority is responsible for your child's wellbeing.

[The Education \(Disability Strategies and Pupils' Educational Records\) \(Scotland\) Act 2003](#)

¹²This act talks about the importance of:

⁷ The Special Educational Needs and Disability (Northern Ireland) Order 2005. Available at: <http://www.legislation.gov.uk/nisi/2005/1117/contents> [Accessed April 27, 2016].

⁸ Legal-Situation-in-Schools.pdf. Available at: <http://medicalconditionsatschool.org.uk/documents/LegalSituation-in-Schools.pdf> [Accessed April 12, 2016].p2

⁹ Education Support for Northern Ireland - Special Education, Dispute Avoidance and Resolution Service (DARS). Available at: <http://www.education-support.org.uk/parents/special-education/dars/> [Accessed April 27, 2016] p3

¹⁰ Legal-Situation-in-Schools.pdf. Available at: <http://medicalconditionsatschool.org.uk/documents/Legal-Situation-in-Schools.pdf> [Accessed April 19, 2016]

¹¹ Children and Young People (Scotland) Act 2014. Available at: <http://www.legislation.gov.uk/asp/2014/8/contents/enacted> [Accessed April 19, 2016].

¹² Education (Disability Strategies and Pupils' Educational Records) (Scotland) Act 2002. Available at: <http://www.legislation.gov.uk/asp/2002/12/contents> [Accessed April 27, 2016]. ¹³ Education

- Your child being able to access educational and connected services
- Having a plan for how your child is supported
- Improving communication between the school, your child and you
- Where to find helpful resources and organisations
- Consulting with all involved parties

[The Education \(Additional Support for Learning\) \(Scotland\) Act 2004¹³](#) says that the Education Authority has a duty to meet, keep and review the requirements of any child with possible additional support needs. This includes pupils with medical conditions. Additional support needs are defined as anything acting as barrier to your child's learning and educational experience.

You have a right to request that your child is assessed for possible additional support needs. You may be offered a co-ordinated support plan, or a review of your child's existing plan.

If you have problems with the assessment you can appeal to the Additional Support Needs tribunal.

Website: asntscotland.gov.uk/

Support

The Enquire website supports parents and carers of children in Scotland with additional support needs. The helpline is open Monday to Friday 9.00 to 4.30.

Tel:

Website: enquire.org.uk/blog/developing-policy-and-legislation/new-rights-for-children-withadditional-support-needs

Extra information on epilepsy in schools in Wales

Local authority and schools policies for children with medical conditions and children with special educational needs in Wales

The guidance for Wales is currently under review. Once the updated version has been published we will update our information. May 2016

(Additional Support for Learning) (Scotland) Act 2004. Available at: <http://www.legislation.gov.uk/asp/2004/4/contents> [Accessed April 27, 2016].

Access to education and support for children and young people with medical needs 2010¹³

This is a long and detailed document which covers all aspects of school life and how your child should be supported. It has key actions points and good practice guides in purple boxes throughout the document. At the end are a number of forms and templates covering areas such as school policy, individual healthcare plans and parental consent forms.

Here are pages for some of the most relevant information:

- Special education needs/statutory assessment p5
- Healthcare plans pp20–22
- School training p24
- School trips p27
- Administering medicines p41
- Guidance on school policies for supporting children and young people with medical needs p72–73

[Access to education and support for children and young people with medical needs 2010](#)

How can I make sure my child is looked after properly while they're in school?

- **The school policy**
- **The individual healthcare plan (IHP)**
- **Epilepsy medicines**
- **What should happen if my child has a seizure in school?**
- **School activities**

The school policy¹⁴

The school must make sure that your child has what they need in order to take part in school life in the same way as anyone else. The school policy should include:

- Who is responsible for making sure there are enough staff trained to help your child
- A commitment that all staff who need to know are aware of your child's medical condition
- Who can provide support for your child, when named staff are not there

¹³ Welsh Government | Access to Education and Support for Children and Young People with Medical Needs. Available at: <http://gov.wales/topics/educationandskills/publications/guidance/medicalneeds/?lang=en> [Accessed April 19, 2016].

¹⁴ [Accessed April 20, 2016].

Stat guidance template - supporting-pupils-at-school-with-medical-conditions.pdf. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/484418/supporting-pupils-at-school-with-medical-conditions.pdf

- Information about your child for supply teachers
- Risk assessments for school visits, holidays and other school activities inside and outside of the normal timetable
- How your child's IHP should be monitored

The individual healthcare plan (IHP) ¹⁵

If you tell school that your child has epilepsy, they must make sure that there are arrangements in place to support your child. They should also make sure that school staff are properly trained to provide this support.

The information about your child's medical condition and specific needs can be recorded in an IHP. This is a very individual document for each child. It makes it clear what specific support your child needs, when it should be provided and who is responsible for making sure that your child gets the support they need.

Not all children with epilepsy will need an IHP. For example, they might only ever have seizures in their sleep, and not have any other effects from their epilepsy. However, if you feel that your child should have an IHP, you should discuss this with their teacher. If there is disagreement about whether one is needed, the head teacher will make the final decision.

An IHP is where most children will have all the important information kept. This should include any educational needs, if these needs are not recorded anywhere else. If your child has both an IHP and an education and health care plan (EHCP) these two plans should be linked together.

To produce an IHP, the school should work together with you and your child, and a relevant healthcare professional. This could be your child's epilepsy specialist or epilepsy specialist nurse or the school nurse.

Here is a recommended list of things to discuss when you are developing an IHP for your child.

- Their type of epilepsy
- Their type of seizures
- What happens before, during and after a seizure
- How long their seizures last
- Appropriate first aid
- What the school should do after your child has had a seizure
- How long your child needs to rest following a seizure
- When the school should call an ambulance
- What the school should do in an emergency

¹⁵ [Accessed April 20, 2016]p9

Stat guidance template - supporting-pupils-at-school-with-medical-conditions.pdf. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/484418/supporting-pupils-atschool-with-medical-conditions.pdf

- Triggers for your child's seizures (if any)
- Any warnings your child has that they may be about to have a seizure (for example a headache or an aura)
- Any medicine they take, and when they need to take it
- Any medicine side-effects that the school needs to be aware of
- Any particular activities that you think may put your child at risk, and what can be done to reduce the risk
- Any adjustments that need to be made to the classroom environment, to support their learning
- Any other provisions the school needs to make, for example extra time in exams
- Any other medical conditions that your child has
- Who the healthcare professionals involved in your child's care are
- Any behaviour or emotional issues that the school needs to be aware of
- Who else in school needs to know about your child's epilepsy – class teacher, dinner time assistants and friends

An IHP should be easy to find for anyone who needs the information, but it should also make sure your child's details stay confidential.

IHPs should be reviewed every year, or earlier if your child's epilepsy or needs change. They should be developed with your child's best interests in mind and ensure that the school assesses and manages risks to your child's education, health and social wellbeing.

Epilepsy Action has templates for IHPs

Epilepsy medicines¹⁶

Daily epilepsy medicines

If your child takes daily epilepsy medicine, you will usually be able to give them their doses outside school hours. The school should only give them medicine during school hours if it would be harmful to their health or school attendance if they didn't.

Emergency medicines

Your child may have been prescribed emergency medicine, to stop seizures that last a long time or clusters of seizures.

Emergency medicines for seizures include buccal midazolam and rectal diazepam:

¹⁶ [Accessed April 20, 2016]p19

Stat guidance template - supporting-pupils-at-school-with-medical-conditions.pdf. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/484418/supporting-pupils-atschool-with-medical-conditions.pdf

- Buccal midazolam is given to the child through a needle-free syringe, between the cheek and gum, and is absorbed through the cheek cells
- Rectal diazepam is given through the child's back passage

Epilepsy Action has more information on seizures that last a long time

The law says that the school should offer any healthcare support necessary for your child. If your child needs their emergency medicine during school time, the head teacher can ask any member of staff to do this. However, the member of staff can refuse to do so and the head teacher will have to find somebody else who will.

The emergency medicine should only be given by a person trained in how to do this by a professional, such as an epilepsy specialist nurse. The people who can give it will be named in your child's [individual healthcare plan](#) (IHP). Some people will have a separate care plan for their emergency medicine. A copy of this should be kept together with the IHP.

The school should keep a record every time your child is given emergency medicine. This should include what was given, how much, when and who by.

The school should keep emergency medicines stored in a safe and secure place, such as a locked cupboard. But they should be very easy to get hold of in an emergency. The expiry dates on the medicine should be checked regularly.

Epilepsy Action has IHPs, buccal midazolam care plans and rectal diazepam care plans

IPSEA and the Council for Disabled Children have templates for school procedure

Website: ipsea.org.uk

Website: councilfordisabledchildren.org.uk/resources

Training in giving emergency medicines

The law and guidance says education and health care needs should be looked at together. This means that the local authority and the local healthcare services should work together to have those needs in place. This should include school staff getting¹⁷

- Their training needs met
- Clear expectations of their role
- Their ability to provide support for the child's medical condition confirmed by a healthcare professional
- Cover arrangements for when they are unavailable

The school's governing body should make sure sufficient staff receive appropriate training.

What should happen if my child has a seizure at school?

¹⁷ [Accessed April 20, 2016]p11

Stat guidance template - supporting-pupils-at-school-with-medical-conditions.pdf. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/484418/supporting-pupils-at-school-with-medical-conditions.pdf

If your child has a seizure at school, any member of staff should know what to do to help. This might involve giving first aid or calling for a named person who knows what help your child needs.

If your child has an individual healthcare plan (IHP), this should have detailed information about their seizures and what first aid they need. IHPs should be easily accessible to all members of staff who might be with your child when they have a seizure.

After a seizure, your child might need to go to the school office or medical room to recover. They should not go there alone. School staff must make sure that a suitable person, such as an adult or a responsible pupil, goes with them.

What should happen if there is an emergency?¹⁸

The school policy should make it clear what should happen in an emergency situation, for any child with a medical condition. If your child has epilepsy, an emergency situation at school would be if they:

- Had a single seizure or cluster of seizures that lasts for longer than five minutes, **or** longer than is usual for them
- Were severely injured as the result of a seizure

All school staff should be able to recognise what is happening and respond quickly. They will need to either:

- Arrange for an ambulance to be called **or**
- Arrange for a named and trained member of staff to give your child emergency medicine **or**
- Arrange for appropriate first aid, if your child has been injured

If your child needs to go to hospital, staff should go with them in an ambulance or stay with them until you arrive at school.

Epilepsy Action has information about first aid and seizures that last a long time

How will people in school know how to respond to an emergency?

School staff

How a member of staff responds will depend on what the emergency is, and whether your child has an individual healthcare plan (IHP). An IHP should give clear and specific instructions about what to do in an emergency, and who should do it.

Here are some ways that the school can make sure that all staff know what to do in an emergency situation:

- All staff should receive general epilepsy awareness training
- When new members of staff start working at the school, they should receive epilepsy awareness training
- Individual healthcare plans should be easily accessible and familiar to all members of staff who need to refer to them

¹⁸ P22

Other pupils

Pupils in school should know to tell a member of staff immediately if your child has a seizure and needs help. The school could give general epilepsy awareness training to the pupils, to make sure they recognise when a child may need help.

Where can the school get epilepsy awareness training?

Epilepsy Action provides:

- epilepsy awareness training through its accredited volunteers
[epilepsy.org.uk/volunteer/accredited/training](https://www.epilepsy.org.uk/volunteer/accredited/training)
- online resources for school staff
- classroom resources for primary school children:
learn.epilepsy.org.uk/?from=mainnav?from=main-nav&from=main-nav&from=main-nav

School activities ¹⁹

Most children with epilepsy are covered by the equality laws in England, Scotland and Wales. In Northern Ireland they are covered by the Disability Discrimination Act. These laws are to make sure your child has the same access to school activities as any other pupil, wherever possible.

Your child should be allowed to take part in all school trips and activities, including those with overnight stays. They should not be prevented from taking part in any activities, unless a healthcare professional advises that the activities are dangerous.

When a school trip or activity is being planned, the organisers should do a risk assessment for your child. This will give them the opportunity to look at what extra help your child might need, because they have epilepsy. They can then decide on what they can do to make sure your child can take part fully and safely. This may involve being flexible and making reasonable adjustments. Reasonable adjustments are things a school might do to make it possible for a disabled child to join in an activity. An example would be having an extra adult on a trip who could take care of the child if they had a seizure.

You and your child should be involved in the risk assessment. You can help the organisers by sharing as much information as you can about your child's epilepsy and the support they might need. You can also suggest reasonable adjustments they could make. The people doing the risk assessment should also get advice from a relevant medical professional, such as an epilepsy specialist or epilepsy specialist nurse.

Epilepsy Action has information about the equality laws, risk assessments, sport and leisure and safety

¹⁹ Stat guidance template - supporting-pupils-at-school-with-medical-conditions.pdf. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/484418/supporting-pupils-at-school-with-medical-conditions.pdf [Accessed April 20, 2016].p21

Will my child have problems with learning and behaviour?

- **What sort of learning could be a problem?**
- **How might epilepsy affect my child's learning?**
- **What sort of help can my child get with learning?**
- **How might having epilepsy affect my child's behaviour and wellbeing?**
- **What should I do if I think my child needs extra support in school? (SEN)**

Epilepsy is a varied condition. Different children will have very different experiences of how epilepsy affects them, and the impact it has on their school life.

Some children with epilepsy have no major problems with their learning or behaviour. Other children with epilepsy (for example, those with some epilepsy syndromes) are severely affected by their condition, and may have significant problems with learning, language or behaviour throughout their lives. These children need extra support. This is so that they can be fully included in the school day and reach their full potential.

Overall, children with epilepsy are at greater risk of learning and behaviour difficulties than children without epilepsy. These difficulties also affect children without identified special educational needs. A recent study found that these difficulties often go unrecognised and unsupported²⁰.

It is important to think about the whole child, and consider all aspects of their life that might be affected by living with epilepsy. This is because learning, behaviour and wellbeing are all related to each other

What sort of learning could be a problem?²¹

A recent study of school children with active epilepsy in West Sussex showed that:

- Over half of the children found it more difficult to learn than other children
- Over half of the children had problems with their memory
- Just under half of the children had problems with the speed with which they processed information
- Just under half of the children were not achieving as much as they could at school. The greatest difficulties were in mathematics and understanding their work
- Six out of 10 parents reported that their child had difficulties with attention and concentration

²⁰ Young Epilepsy (2014), "The identification of educational problems in childhood epilepsy: The Children with Epilepsy in Sussex Schools (CHESS) Study" p. 4

²¹ Young Epilepsy (2014), "The identification of educational problems in childhood epilepsy: The Children with Epilepsy in Sussex Schools (CHESS) Study" p. 4

How might epilepsy affect my child's learning?

- **Causes of epilepsy**
- **The effects of seizures**
- **Side-effects from epilepsy medicines**
- **Absence from school**
- **Related conditions**

Causes of the epilepsy

For some children, difficulties with learning can be caused by damage to their brain, which also causes their epilepsy. This damage could have happened before, during, or after their birth. Some children with some epilepsy syndromes are more likely to have learning difficulties than others.

The effects of seizures

Epileptic seizures can disrupt normal brain activity, and this can stop memory from working properly. The confusion that can happen for your child after a seizure may also cause memory loss.²²

Some children have a lot of epileptic activity in their brain, but don't appear to be having any seizures. This can happen when your child is awake or asleep. If this happens very frequently, it can also affect your child's memory and how they learn.

Depending on the type of seizures a child has, they may feel very tired or confused after a seizure. They may also have interrupted sleep which will make them tired. Feeling tired or confused can affect how well a child can learn.

The more seizures a child has, the more pieces of information they will miss. For example, if a child has hundreds of short absences in a day, they will miss many little bits of information. This will make gaps in their learning.

Side-effects from epilepsy medicines

The majority of children and young people with epilepsy are treated with epilepsy medicines. These don't just reduce the numbers of seizures a child has. They also affect the way the brain controls all its electrical impulses. This is why epilepsy medicines can have an effect on your child's learning.

Some children may have side-effects that affect their learning. These could include hyperactivity, irritability, aggression, drowsiness, dizziness, memory problems, problems concentrating and mood swings.²³

Epilepsy Action has more information about children and epilepsy medicines

²² Epilepsy Action, 2011. *Memory* [online]. Available at <http://www.epilepsy.org.uk/info/memory> [Accessed 2 July 2013]

²³ BNF 71

Absences from school

Some children miss parts of their education because they need time off school to go to appointments with the nurses and specialists who manage their conditions. They may also be absent as a result of seizures, recovery after a seizure or injuries from a seizure. If these are significant, you may want to talk to the school about possible reasonable adjustments for your child to catch up with missed lessons.

Related conditions²⁴

A recent study of school children with active epilepsy in West Sussex showed that 6 out of 10 of the children showed some symptoms of at least one of the following disorders:

- Attention deficit hyperactivity disorder
- Autism spectrum disorder
- Developmental co-ordination disorder
- Depression or anxiety

Only 2 in 10 of these had been diagnosed with one of these conditions. This is worth bearing in mind if your child is struggling with their learning.

What sort of help can my child get with learning?

- Reasonable adjustments
- Individual healthcare plan
- Support at exam time
- What should I do if I think my child needs extra support in school?
- Epilepsy Action resources

Reasonable adjustments

Identify any 'risks' for your child with learning. Answers to our [risk assessment questions](#) may help you with this. The table gives some examples of possible risk and reasonable adjustments.

Possible risks	Possible reasonable adjustments
Missing information because of absence seizures	Having a teaching assistant to watch for and provide information missed
Missing information because of absence from school	Having teacher provide notes from missed lessons
Swimming lessons	Having extra adult to watch for seizure activity
Chemistry lessons	Working in pair with someone responsible who could make situation safe if seizure happened

Individual healthcare plan

Any action which has been identified to help will need to be agreed between you and the school and included in your child's individual healthcare plan.

²⁴ Young Epilepsy (2014), "The identification of educational problems in childhood epilepsy: The Children with Epilepsy in Sussex Schools (CHESS) Study" p. 4

Support at exam time

It may be possible for your child to get help at exam time.

What should I do if I think my child needs extra support in school?

First you need to ask the local authority if they will do an assessment. They will say yes or no. If they say yes, they will first look at whether your child needs special educational needs support. Here are some examples:

- Extra help from a teacher or assistant
- Working in a smaller group
- Observation in class or at break
- Help taking part in class activities
- Extra encouragement in learning, for example encouraging the child to ask questions or to try something they find difficult
- Help communicating with other children
- Support with physical or personal care difficulties, eg eating, getting around school safely or using the toilet

After this assessment the local authority will decide if your child needs any of the things on the list.

If you or the local authority think that your child needs more than is offered by a special educational needs support you will need to ask them to do an education, health and care assessment (EHCA). This used to be called a statement.

How do I get an education, health and care assessment for my child?²⁵

The first person to talk to would be your child's teacher or the school's special educational needs co-ordinator (SENCO). They could give you some guidance on how to apply to your local authority for an assessment (EHCA) for your child.

The local authority must:

- Consider requests for assessment
- Consult with the relevant people
- Make a decision within 6 weeks of the request about whether an assessment will be carried out

What is an education, health and care plan (EHCP)?

In order to get a plan for your child you will need to ask your local authority. A decision about whether a child needs special educational provision must be made within 16 weeks of the request. If the local authority says the child doesn't have a special educational need, you, as the parent can appeal to [the SEND Tribunal](#).

²⁵ ChildrenAndFamiliesActBrief.pdf. Available at: <http://www.councilfordisabledchildren.org.uk/media/554523/ChildrenAndFamiliesActBrief.pdf> [Accessed April 19, 2016]

If the local authority says your child does have a special educational need requiring an EHCP, the EHC checklist must be completed. The local authority must send a draft to you, as the parent with 15 days for you to give feedback. Then a copy including a named school if relevant must be sent to you and the named school.

If the local authority agree that your child needs an EHCP, they will then draft the plan and send it to you for comment. There are strict time lines for this communication. The assessment or your comments on it might include a request for your child to attend a special needs school. It might include a recommendation that you have a personal budget for your child's education. The plan should include what the needs of your child are and what the extra help should be.²⁶ A checklist should include:

- The views, interests and hopes of your child
- Special educational needs (SEN)
- Health needs related to SEN
- Social care needs related to SEN
- Outcomes - how the extra help will benefit your child
- Special educational provision (support)
- Health provision
- Social care provision
- Placement - type and name of school or other institution
- Personal budget arrangements. This is the amount of money a local authority gives you for your child, based on an assessment of your needs
- Advice and information - a list of the information gathered during the EHC needs assessment

The plan should be reviewed every year. It can last up to the age of 25.

You can find out more about your local authority's policy on special educational needs, by searching using the name of your local authority and the words "local offer".

Here are some organisations that would be able to help you with applying for an EHCA:

Council for Disabled Children:

Website: councilfordisabledchildren.org.uk/independentsupport

Contact a Family

Website: : cafamily.org.uk/advice-and-support/education/

Information, Advice and Support Service Network

Website: iassnetwork.org.uk/find-your-iass/

²⁶ Education, Health and Care (EHC) plans | Contact a Family. Available at: [http://www.cafamily.org.uk/adviceand-support/education/education-health-and-care-\(ehc\)-plans/](http://www.cafamily.org.uk/adviceand-support/education/education-health-and-care-(ehc)-plans/) [Accessed April 27, 2016]. ²⁸ Appeal to the Special Educational Needs and Disability Tribunal - GOV.UK. Available at: <https://www.gov.uk/special-educational-needs-disability-tribunal/print> [Accessed April 25, 2016].

If the local authority don't agree that your child needs an assessment or plan, you have the right to appeal.²⁸ This would be to the Special Educational Needs and Disability (SEND) Tribunal.

Website: [gov.uk/special-educational-needs-disability-tribunal/overview](https://www.gov.uk/special-educational-needs-disability-tribunal/overview)

Epilepsy Action resources

Epilepsy Action has more information on supporting pupils with specific learning or behaviour issues in the online learning section of our website. The topics include:

- Memory
- Attention and concentration
- Speech and Language difficulties
- Behaviour problems

It also has video clips of four young people talking about their learning experience.

How might having epilepsy affect my child's behaviour and wellbeing?

Medical/physical issues

- Causes of epilepsy
- The effects of seizures
- Side-effects from epilepsy medicines
- Related conditions

Social/emotional issues

- Why has my child's behaviour changed?
- If my child's behaviour changes what can I do about it?
- How can the school support my child?
- What can I do to help the school support my child?

Medical/physical issues

Causes of the epilepsy

For some children, difficulties with learning can be caused by damage to their brain, which also causes their epilepsy. This damage could have happened before, during, or after their birth. Some children with some epilepsy syndromes are more likely to have learning difficulties than others.

The effects of seizures

Some children may behave differently in the time before, during and after a seizure. In the hours or even a few days before a seizure, a child's mood or behaviour may also change. This is called a prodrome.³⁰

During a focal seizure, it's quite usual for a child to appear to be behaving differently. These behaviours may include gagging, lip smacking, running, screaming, crying, and/or laughing. They may not be conscious of what they are doing, but they are in fact having a seizure.³¹

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²⁹ Dunn W, Dunn MD et al, (2002) *Behavioural issues in paediatric epilepsy* [online] Available at <http://www.psychiatrictimes.com/articles/behavioral-issues-pediatric-epilepsy> (Accessed 18 October 2013) ³⁰ Besag, FM, Subtle cognitive and behavioural effects of epilepsy, in the Neuropsychiatry of epilepsy [online] available at <http://bit.ly/19jxWgY> (Accessed 12 April 2016) p39

After a seizure, it's quite usual for a child to be confused, have a headache, feel sleepy or have problems with vision or speech. This can also change their behaviour.

Very rarely, a child might have a condition called post-ictal psychosis.²⁷ This can be very frightening and can change a child's behaviour. It can cause them to have a strong belief that something unreal is true, or hear or see things that are not there.

Side-effects from epilepsy medicines

Some children may have side-effects that affect their learning. These could include hyperactivity, irritability, aggression, drowsiness, dizziness, memory problems, problems concentrating and mood swings. ³³

²⁷ Kaur, M et al, *Postictal psychosis in a 3 year old child* [online] Available at <http://www.ncbi.nlm.nih.gov/pubmed/22532553b> [Accessed 26 November 2013] ³³ BNF 71

Epilepsy Action has more information about children and epilepsy medicines

Related conditions

A recent study of school children with active epilepsy in West Sussex showed that 60 percent (60 in 100) of the children showed some symptoms of at least one of the following disorders: attention deficit hyperactivity disorder, autism spectrum disorder, developmental co-ordination disorder, depression or anxiety. Only 20% (20 in 100) of these children had been diagnosed with one of these conditions.^{28,29}

Social and emotional issues (How might having epilepsy affect my child's social and emotional wellbeing?)

Children with epilepsy are at higher risk of behavioural, emotional, psychiatric and social problems than children without epilepsy. This risk is also higher than for children with other long-term health conditions and sensory impairments.

Why has my child's behaviour changed?

There are many ways in which your child may be affected by their diagnosis.³⁰ They may:

- ³¹ Be self-conscious of their epilepsy
- Be frightened that they are going to have a seizure
- Experience anxiety or depression because of their epilepsy
- Be bullied because they have epilepsy
- Have frequent short-term absences from school, due to medical appointments or seizures, causing them to miss some school activities
- Have long-term absences from school because of their epilepsy and need help to get back into their school routine
- Experience side-effects from epilepsy medicine, which could include drowsiness, dizziness, memory problems, problems concentrating and mood swings
- Feel very tired, because they are recovering from a seizure or have had disturbed sleep
- Have another condition which is also affecting how they feel and how they learn

It is important that the school is aware of these possible things your child might be going through. They could all have an effect on your child's learning and emotional wellbeing.

If my child's behaviour changes what can I do about it?

²⁸ CHESS-report-March-2014_summary.pdf. Available at: <https://trello-attachments.s3.amazonaws.com/529745e31dec6f54230052be/534422e4e85383bb487a5394/f2483ea0c4b25f96f>

²⁹ <https://trello-attachments.s3.amazonaws.com/529745e31dec6f54230052be/534422e4e85383bb487a5394/f2483ea0c4b25f96f> [Accessed July 8, 2014]p3

³⁰ Stat guidance template - supporting-pupils-at-school-with-medical-conditions.pdf. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/484418/supporting-pupils-at-school-with-medical-conditions.pdf [Accessed April 20, 2016]p.5

³¹ JohnHopkins Medicine (undated) Seizures and epilepsy in children [online] Available at http://www.hopkinsmedicine.org/healthlibrary/conditions/pediatrics/seizures_and_epilepsy_in_children_90,P02

The first thing to work out is where the behaviour is happening and who with. If the changed behaviour is happening everywhere, there may be a medical cause. If the change is only happening at home, or at school, it may be worth looking at what might be happening in that particular setting.

Here are some questions to help you work out where the problem might be.

Ask yourself

- Where is it happening?
- What is their teacher saying about how they are in school?
- What do other family members think is happening for your child?
- Can you identify any particular triggers for the behaviour?
- Are they being bullied?
- Has it started happening at the same time as a change of epilepsy medicine?
- Has it changed at the same time as poorer seizure control?
- Are there any seizure triggers that might be avoided?
- Do they need to see the specialist to check for underlying seizure activity?
- Are they getting stressed? Do they need help with staying more relaxed?

The answers to these questions will help your family, the school and the specialist to work out what is affecting your child's behaviour and what it is a good idea to do about it.

Keeping a seizure diary is a really good way of seeing if there may be a link between the timing of a change in epilepsy medicine and the timing of a behaviour change.

Epilepsy Action has seizure diaries

Coming to terms with the diagnosis

It can be really difficult to come to terms with a diagnosis of epilepsy. This can affect all members of the family in different ways. As a parent finding a way for you to come to terms with your child's diagnosis and feel less anxious, may help your child do the same.

When your child is first diagnosed it may be a challenge to find a balance between keeping them safe and allowing them their independence. Many parents find that helping their child maintain as much independence as possible helps with their general wellbeing. This should help them come to terms with the epilepsy. And the more positive your child feels the more likely it is that other people will not see his or her epilepsy as a problem.

It is very easy to put all your attention into the child with the diagnosis. Try to make sure any siblings are included in sharing information about what has happened and how you are going to adapt as a family. This is also likely to help the child with epilepsy accept their condition with less fuss.

[Information for siblings](#)

How can the school support my child?

The school should be aware of ways that your child's epilepsy might have an effect on their behaviour and wellbeing.

The school should make sure that your child receives the support they need to deal with these issues. To help them do this, they should get advice from relevant healthcare professionals. They should also listen to, and value the views of you and your child about how they can do this.

It is important to bear in mind that anything that affects a child's behaviour and wellbeing can have an effect on how well they learn. Helping your child reach their potential as a whole person should be a key focus of education. **Bullying**

For any child who is different there is a risk that they may be bullied.

Contact a Family have detailed information and guidance on how to support your child if you think this is happening to them.

cafamily.org.uk/advice-and-support/education/bullying/

What can I do to help the school support my child?

You have a very important role in helping school to provide your child with the support they need. Here are some ways you can help:³²

- Keep the school up-to-date with detailed information about your child's epilepsy and needs. This is especially important if there are any changes in their condition or treatment
- Find a means of communicating important information with the school in a way that works for both of you. This is likely to include you and school staff being able to record information on a daily basis. Some people use a communication book for this
- Make sure you carry out any responsibilities listed in your child's individual healthcare plan
- Go to all the meetings that you are invited to. Try to think beforehand about any information you can provide that will be helpful
- Make sure that the school are easily able to contact you, if there is an emergency
- If it is needed, make sure that the school has the correct rescue medicine. This needs to be in date, clearly labelled and in the correct container
- Make sure your child knows who to tell if they get a warning of a seizure
- Even if you feel angry about the way you or your child has been treated, a calm, organised approach to the conversations with the teachers will usually get a better result

What should I do if the school is not offering what I think my child needs?

³² Stat guidance template - supporting-pupils-at-school-with-medical-conditions.pdf. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/484418/supporting-pupils-at-school-with-medical-conditions.pdf [Accessed April 20, 2016].p13

First make sure the school know what is happening for your child and what your concerns are. If you've tried talking to one person and are not happy with the response, try someone else. Here is a list of people in school it might be worth speaking to. It will vary depending on the type of school.

- Class teacher
- Form tutor
- Special educational needs co-ordinator (SENCO)
- Head of year
- Deputy head
- Head of school
- School governors

If the school and children need epilepsy awareness training, Epilepsy Action can help with that.

- [Epilepsy awareness training from a volunteer](#)
- Epilepsy awareness training online for [school staff](#)
- Epilepsy awareness resources online for [primary school children](#)

If you are not happy with the school's response you could make a formal complaint using the school's complaints procedure.³³

See our list of useful organisations for help with this.

What should I do if I think the school is supporting my child really well?

Nominate them for an Epilepsy Action best practice education award, It's called an [Edwards Award!](#)

Home to school transport

Some children and young people with epilepsy may be eligible for help with school transport. This is the responsibility of the local authority.

Their duty is described in the [home to school travel and transport guidance](#)³⁴

When assessing your child, your local authority should consider your child's individual needs. They should consider:

- The walking distance between home and school

³³ Stat guidance template - supporting-pupils-at-school-with-medical-conditions.pdf. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/484418/supporting-pupils-atschool-with-medical-conditions.pdf [Accessed April 20, 2016].p24

³⁴ Department for Education - Home_to_School_Travel_and_Transport_Guidance.pdf. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/445407/Home_to_School_Travel_and_Transport_Guidance.pdf [Accessed April 25, 2016].p10

- The safety of the route
- Your family and social circumstances
- Your child's health, additional needs and/or disability

It may well be useful for the local authority to be aware of your child's individual healthcare plan. This will help them develop a separate transport healthcare plan.³⁵

Each local authority organises home to school transport slightly differently. To find your local information follow the links below. For pupils in [England](#)

Website: [.gov.uk/help-home-school-transport](https://www.gov.uk/help-home-school-transport)

For pupils in [Northern Ireland](#)

Website: nidirect.gov.uk/articles/school-transport

For pupils In [Scotland](#)

Website: enquire.org.uk/20100622/wp-content/uploads/2010/11/transport-to-school.pdf

For pupils in [Wales](#)

Website: legislation.gov.uk/mwa/2008/2/contents

Help with exams

This information is for people who may need help with GCSE or GCE exams. Most of this will be relevant wherever you live in the UK. There is some slightly different information for Scotland.

Website: sqa.org.uk/sqa/70972.html

Exams are a difficult time for just about everybody. But if you have epilepsy there can be extra problems.

Possible seizure triggers and how to look after yourself

We have heard that stress and lack of sleep are common seizure triggers. These are both very common for people around exam time. So one thing you can do for yourself is to make sure you try everything you can to keep some control of your stress levels. And that you generally do what you can to keep yourself healthy during this time. There are many ways to do this. Some people find it useful to practice them for a while to make sure are really familiar with them, so they are automatic by the time you really need them.

Epilepsy Action has information on [stress](#) and [wellbeing](#)

³⁵ Stat guidance template - supporting-pupils-at-school-with-medical-conditions.pdf. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/484418/supporting-pupils-atschool-with-medical-conditions.pdf [Accessed April 20, 2016p25]

Support at exam time

This information is for all schools in the UK

Access arrangements³⁶

If you can predict what you may need before the exam starts, then talk to your special educational needs co-ordinator (SENCO). Tell them how you think your epilepsy could affect your exam performance. You need to do this as soon as possible because it can take some time to get special arrangements in place. And there are official deadlines that need to be met.

The SENCO will need to know what sort of problems you may have. They will need medical evidence such as a letter from your neurologist, to support this. They will put the claim together including suggested reasonable adjustments and send it to the Joint Council for qualifications (JCQ). The JCQ will decide if they agree that you need the reasonable adjustment. If they say no, you have the right to appeal.

The aim of access arrangements is:⁴¹

- To allow you to access the exam **and**
- To be able to show what you know and can do without changing the demands of the assessment

The adjustments are made under the Equality Act 2010. This applies if you would be at a “substantial disadvantage from other people”. In this situation the JCQ has to consider possible reasonable adjustments.

- They have to be reasonable **and**
- They have to be apply to you specifically **and**
- They can apply to an individual exam or all exams

If you already have special educational support you are much more likely to be able to get reasonable adjustments at exam time.

Here are some examples of the types of help you may be able to get:³⁷

- Having supervised rest breaks during an exam
- Having an exam supervisor to sit with you to make a note of any seizures you might have during the exam. They would then allocate you extra time at the end of that exam
- Taking an exam at a different time of day or place to other people who are taking the same exam. For example, if you usually have seizures first thing in the morning, you might be able to take the exam in the afternoon
- Getting one-to-one support for practical exams

³⁶ Access Arrangements and Reasonable Adjustments 2015-2016 - JCQ Joint Council for Qualifications. Available at: <http://www.jcq.org.uk/exams-office/access-arrangements-and-special-consideration/regulationsand-guidance/access-arrangements-and-reasonable-adjustments-2015-2016>

[Accessed April 26, 2016]. ⁴¹ P30

³⁷ P15

Special consideration³⁸

Special consideration is a scaling up of your marks or grade after your exam. Here is how the JCQ explain the circumstances in which you might get special consideration:

“Special consideration is a post-examination adjustment to a candidate’s mark or grade to reflect temporary illness, temporary injury or other indisposition at the time of the assessment, which has had, or is reasonably likely to have had, a material effect on a candidate’s ability to take an assessment or demonstrate his or her normal level of attainment in an assessment.”³⁹

Your grade can be increased by up to five per cent depending on circumstances.⁴⁰ The JCQ recommends an increase of three per cent for a person who has a seizure.⁴¹

The exam board takes into account the marks you got in previous exams or course work in that subject. They may also ask your teacher about other work you have done on the course. A certain amount of the total assessment (course work, practical or exams) must have been completed in order for special consideration to be possible.

When you might get special consideration

You may be given special consideration if, for example, you have a seizure that affects your performance in an exam. The seizure doesn’t necessarily have to happen during an exam. It could happen before the exam, but still be affecting your performance during the exam. Special consideration could be given if you attend an exam but are disadvantaged compared to other candidates. It might also be given if you are absent from the exam because of illness.

How to apply for special consideration

Talk to the SENCO or exams officer at your school or college. They will then ask for special consideration on your behalf.

The application for special consideration must be made within seven days of the exam. You may need to get a letter of support from your doctor to show that you were unable to start or complete the exam. The exams officer should be able to tell you what you need.⁴²

Further information

- [Joint Council for Qualifications](#)
- [Advisory Centre for Education \(ACE\)](#)
- [Extra information for Scotland](#)

³⁸ Access Arrangements, Reasonable Adjustments and Special Consideration - JCQ Joint Council for Qualifications. Available at: <http://www.jcq.org.uk/exams-office/access-arrangements-and-special-consideration> [Accessed November 5, 2014].

³⁹ P3

⁴⁰ P6

⁴¹ P7

⁴² P13

Epilepsy Action has more information about [triggers of seizures](#), [diagnosis](#) and [seizures](#).

Useful organisations

Department for Education (England)

This offers a wide range of information about educational issues. The website link goes directly to the new guidance on supporting pupils at school with medical conditions. It also includes templates for schools

Website: gov.uk/government/uploads.pdf

IASS Network

IASS used to be called the Parent Partnership network. They are an information, advice and support service network. They have a duty to provide information, advice and support to disabled children and young people, and those with special educational needs, and their parents. There should be an IAS Service in every local authority. **Website:**

iassnetwork.org.uk

Contact a Family

Contact a Family offers advice and information on special educational needs. You can speak to specialist education advisors on their helpline.

Tel: 0808 808 3555

Website: cafamily.org.uk/advice-and-support/sen-national-advice-service/

ACE Education

ACE gives advice and information on education issues. It covers state funded education for children aged 5-16 years in England only.

The advice line is open Monday to Wednesday 10 till 1pm in term time. **Tel:**

0300 0115 142

Website ace-ed.org.uk

IPSEA

The Independent Parental Special Educational Advice service offers free and independent legally based information and advice. For parents of children with special educational needs and disabilities. They have a set of model letters for parents to use. The advice line is run by volunteers. **Website:** www.ipsea.org.uk

Child Law Advice Service

The Child Law Advice Service provides legal information and representation on issues of the child, family and education law relating to children and young people. At the website follow the link to the Child Law Advice Service for a range of factsheets and 'how to' guides. The helpline is available Monday to Friday 8am to 6pm.

Tel: 0300 330 5485

Website: childrenslegalcentre.com

Network81

Network81 offers advice and support to parents of children with special educational needs. The helpline is run by volunteers. **Tel:** 0845 077 4055

Website: network81.org

Young Epilepsy

Young Epilepsy supports young people with epilepsy and associated conditions. They also provide epilepsy related training.

Tel: 01342 831 34

Website: youngepilepsy.org.uk

SEN Magazine

SEN publishes a magazine every two months covering all issues to do with special educational needs and disability.

BILD

The British Institute of Learning Disabilities provides support and training resources for those working with people with learning disabilities. **Website:** bild.org.uk

Council for Disabled Children

A website of resources for schools and school healthcare professionals. **Website:** councilfordisabledchildren.org.uk/resources

About this information

This information is written by Epilepsy Action's advice and information team, with guidance and input from people living with epilepsy, and medical experts. If there is anything you would like to say about the information, please contact us at [e_____](mailto:)

Epilepsy Action makes every effort to ensure the accuracy of information but cannot be held liable for any actions taken based on this information. **Date:** August 2016

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Your support

We hope you have found this information helpful. As a charity, we rely on donations to provide our advice and information. If you would like to make a donation, here are some ways you can do this.

- Visit www.epilepsy.org.uk/donate
- Text **ACT NOW** to **70700** (This will cost you £5 plus your usual cost of sending a text. Epilepsy Action will receive £5.)
- Send a cheque payable to Epilepsy Action to the address below.

Did you know you can also become a member of Epilepsy Action from as little as £1 a month? To find out more, visit epilepsy.org.uk/join or call 0113 210 8800.

Epilepsy Action Helpline

Freephone 0808 800 5050, text 0753 741 0044, email helpline@epilepsy.org.uk, tweet [@epilepsyadvice](https://twitter.com/epilepsyadvice)

Contact details

Epilepsy Action, Gate Way Drive, Yeadon, Leeds LS19 7XY, UK, +44 (0)113 210 8800. A registered charity (No. 234343) and company limited by guarantee (No. 797997) in England.

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