

Information leaflet

Supporting a child with chronic health needs

Managing the physical and emotional needs of a child with a long-term health condition can be highly demanding, particularly for older carers who may have health issues of their own.

Children with common chronic health conditions including diabetes, epilepsy and asthma are twice as likely to suffer from emotional problems or disturbed behaviour especially if their condition affects their brain.

Children of special guardians who have suffered neglectful childhoods are more frequently diagnosed with chronic conditions linked to poor parental care. Many will also have other behavioural needs as a result of attachment issues and traumatic experiences they have faced.

Understanding who to approach and what help is available is often itself a major source of stress.

Health history and developmental delays

When children go into local authority care they are legally required to have an initial assessment of their health. This should cover:

- Their mother's pregnancy, the child's birth and early development as well as the birth family's medical history.
- The child's medical history including their experiences of abuse and neglect and their mental health.
- Current physical health including vision, hearing, dental care, immunisations, injuries and illnesses.

This assessment takes place every six months until the child reaches the age of five and then at least every year. However, if a child has been moved between placements things can get missed. Adolescents have the right to refuse to be assessed at all.

In addition there is an increasing recognition that some long-term conditions caused by neglect and abuse, such as Foetal Alcohol Syndrome, are under diagnosed. It is important to ask your GP if there are any health issues you may need to monitor and support. Health conditions can be difficult to diagnose and it can be impossible to predict their long-term impact or what support might be needed in the future.

The impact of long-term health conditions on children

Children with long-term health conditions often need daily on-going medication and monitoring. Their condition can lead to them being away from school for long periods of time which can result in their learning being delayed.

At school and around other children, a child might feel that their condition makes them different to others and as a result develop anxieties about their condition. They might have fewer opportunities to learn everyday skills and to develop their interests and hobbies.

Some children might not feel worthy of treatment or care due to their traumatic experiences. As they move into adolescence their behaviour can become reckless and unpredictable which leaves them at risk to complications of not taking medication or following treatment.

Individual healthcare plans

All children with a long standing illness are entitled to support in school using an individual healthcare plan. This outlines how their medical needs can be properly supported at school and what other support they require to ensure they achieve their full potential and enjoy the same opportunities as their peers.

If your child is changing schools and has a new or recently changed diagnosis or is coming back to a school after a long period of absence, you or a health professional will need to inform the school. The head teacher or a senior staff member will organise a meeting to discuss your child's needs and they should identify a member of school staff to provide support to your child.

An individual healthcare plan should set out:

- Your child's personal details with a photo so staff know who they are.
- Your contact details and those for the child's GP, consultant or clinic.
- The name of the condition and a description of how it affects your child.
- Your child's daily medication regime including dose, storage and side effects.
- Your child's needs around food and social needs such as extra time between lessons.
- Details of what a medical emergency would be for the child and what to do if there is one.
- Their special educational needs if they don't have an Education, Health Care (EHC) plan.

You're advised to review the plan with the school at least once a year or more often if their medication changes or your child's condition is unstable.

Your head teacher will discuss with you and your child, if they're old enough, who will see the plan. The plan is confidential and will only be seen by those who need to provide medical or emergency care. This might include the head teacher, the class teacher and support staff. Outside the school the GP or school nurse may also be involved.

The school should have a policy setting out how it supports children with long-term conditions, this should be available on their website or you can ask for a copy. This will set out its general approach to administering medicines, staff training and how staff ensure pupils can take part in PE and school trips. It also sets out transitional arrangements between schools.

Your school nurse or health visitor for younger children can also provide advice, support and liaise between internal and external professionals or School Health Teams.

Common Assessment Framework (CAF)

A Common Assessment Framework (CAF) might be a useful tool for the school as this joins up care from different services around the child and is an opportunity to talk about your child's progress and review any difficulties their condition is causing.

Education, Health and Care (EHC) Plans

Education, Health and Care (EHC) are primarily put in place for children with special educational needs (SEN) but if a child's long-term health condition is very difficult to manage and it impacts on their ability to learn they may be eligible for one.

An EHC Plan should not be needed unless there are specific individual circumstances.

If you feel your school is not providing the help and support your child needs and this is holding them back, you or your school can request an EHC assessment by contacting your local authority.

Practical tips

- The GP should always be your first port of call as they will hold your child's primary health record. It is important to be clear about any worries you may have or describe what's been happening at home. This can be difficult if you're not used to doing it. Writing points down beforehand can help.
- Health appointments can be difficult particularly for older children as the topic of their change of care arises when medical history is discussed. You can help make the appointment go more smoothly by making sure the GP or consultant is aware of their situation in advance.
- Many health charities provide templates for individual healthcare plans, such as Epilepsy Action and Diabetes UK. These can be helpful for both you and your child's school in making sure their needs are identified correctly.
- Schools should have anti-bullying policies in place for all children who are at increased risk of bullying including those with health conditions.
- Children who have been in care for a while often have neglected teeth and poor dental hygiene. You can find your local NHS dentist by calling 111. Community or specialist dental services offer care to children with challenging behaviour or anxiety who can't access care from NHS dentists for free until they turn 18.

- It is understandable that you will be protective of your child but it is important to allow them to live as normal a life as possible. Encourage them to meet children of their own age and be open with them about their difficulties.

Key points

- It is very important to ask your GP if there are any health issues you may need to monitor and support.
- Children with long-term health conditions often need daily on-going medication and monitoring. Their condition can lead to them being away from school for long periods of time which can result in their learning being delayed.
- All children with a long standing illness are entitled to support in school using an individual healthcare plan.
- A Common Assessment Framework might be a useful tool for the school as this joins up care from different services around the child.

If a child's long-term health condition is very difficult to manage and it impacts on their ability to learn they may be eligible for an EHC Plan.

Useful organisations

Acorns

www.acorns.org.uk

ACORNS offer a network of support for life-limiting or life threatening children, babies and families and related complex needs including short breaks, emergency and end of life care.

ADDIS

www.addiss.co.uk

This charity provides a wide range of people-friendly resources about all aspects of Attention Deficit Hyperactivity Disorder and associated conditions, with special sections for parents, children, teenagers and professionals.

Contact a Family

www.contact.org.uk

Helpline: 0808 808 3555

Contact a Family is a national charity for disabled children, providing information, advice and support services.

Diabetes UK

www.diabetes.org.uk

Helpline: 0345 123 2399

National charity Diabetes UK provides online resources useful to all parents of children with long-term illnesses on the procedures around working with your school to make sure your child gets the best care and learning.



Epilepsy UK

www.epilepsy.org.uk

Epilepsy UK's website explains school support and the range of laws that enforce them, learning and behaviour, education after 16 and resources for schools.

Foetal Alcohol Spectrum Disorder Trust

www.fasdtrust.co.uk

Helpline: 01608 811599

The FASD Trust promotes improving understanding and provides advice and support regarding Foetal alcohol syndrome.

National Organisation for Foetal Alcohol Syndrome

www.nofas-uk.org

A charity dedicated to supporting people affected by Foetal Alcohol Spectrum Disorders (FASD) and their families and communities. It provides information for parents following a diagnosis of FASD, national helpline, support groups and training. Sometimes run free courses for carers.

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