



Your child and special educational needs

This information sheet gives you information and guidance if your child has special needs and needs extra support at school.

Most children with heart conditions will have no problems at school.

However, some children with heart conditions may need extra help at school.

Special needs at school

A difficult start to life may mean some children with heart conditions find it hard to keep up with children of the same age.

Some children with heart conditions are also likely to have other difficulties, including the following.

- Physical limits – your child may not be strong enough to take part in playground or physical activities. Some children may also need help with opening toilet doors, turning taps on, carrying a bag of books, using stairs, and so on.
- Learning disabilities – some children may have learning disabilities as a result of earlier surgery or due to conditions that can happen alongside some heart conditions, such as Asperger's syndrome.
- Social difficulties – some children may find it difficult to communicate clearly or interact with other children.

The needs of children with heart conditions can also vary according to the stage of treatment or recovery they are at.

For example, after surgery they may be very well for a while, but then gradually develop more problems as they outgrow previous surgery.

Taking action

If you have concerns about your child, you should explain these to the school and ask them to take action.

The school will have a policy on dealing with children with special educational needs (SEN), which you can ask to see. The levels of action the school can take are as follows.

Assess, Plan, Review, Do – The Graduated Response:

Your child's head teacher or SENCo/InCo (Special Educational Needs Coordinator/Inclusion Coordinator) can put together an Individual Support Plan (ISP) outlining:

- your child's needs;
- what action will be taken to help your child;
- how often;
- ways in which you can help your child
- what your child can do to help themselves
- what should be achieved (targets); and
- when progress will be reviewed.

If the school feels your child would benefit from involvement from outside services or professionals, they will discuss this with you and request it with parental consent only.

If it is felt that your child's needs cannot be completely met within the universal services available in mainstream educational settings, you or your child's school can request a statutory assessment of their special educational needs.

This assessment may lead to an **Education, Health and Care Plan (EHCP)**, which has replaced the previous Statement of Special Educational Needs.

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Reasons for needing an EHCP

Some children with more significant learning disabilities or complex needs may require an EHCP. There are also physical reasons why children with heart conditions might benefit from an EHCP, such as:

- difficulty walking upstairs, carrying books
- opening heavy doors, and so on;
- breathlessness;
- unstable heart rhythm;
- having a nasogastric or gastrostomy tube for feeding; and
- long periods away from school due to illness or being in hospital.

The Statutory Assessment Process (20 weeks)

Once you or the school have asked for a statutory assessment, the LEA must decide within six weeks whether or not to carry it out. They will consult you, the school and other health professionals before making their decision.

The LEA will write to say whether they are going to carry out an assessment and if so, they will:

- say how they will carry it out and the timescales;
- give you the name of a contact at the LEA ; and
- ask you to give your reasons and provide evidence for why your child should be assessed. (You have at least 29 days to do this.)

If the LEA refuse to do an assessment, they should tell you:

- why not; and
- how your child's needs can be otherwise met.

If this is the case, talk to the school about extra help that could be arranged without an assessment.

Or you can appeal against the LEA's decision through the Special Educational Needs Tribunal.

You can also contact the Special Educational Needs and Disability Information Advice and Support Service (SENDIASS) for independent advice and support. (We provide contact details at the end of this information sheet.)

The LEA assessment

If the LEA agree to do the assessment, they will ask various people to give their views on your child. They usually ask for advice from:

- your child's school;
- an educational psychologist;
- a doctor;
- social services (if they know your child); and
- anyone else they think is appropriate.

You will also be asked for your views, and they may also talk to your child.

You can also suggest any other groups or professionals you know may be helpful, for example, your child's cardiac liaison nurse or a dyslexia expert.

A statement of SEN

Once they have done the assessment, the LEA will decide whether or not to make a statement of SEN within 12 weeks.

If they decide not to make a statement, the LEA will explain how they think your child's needs should be met. If you disagree with the LEA's decision, you can appeal to the Special Educational Needs Tribunal, or use the disagreement resolution service.

How the Statement is put into practice

At first, the LEA will send a draft statement describing your child's needs and the measures needed to tackle them.

It is important to check if the statement:

- lists all of your child's needs and difficulties;
- lists everything your child needs;
- gives details of any special equipment your child needs; and
- is easily understood.

If you are unhappy with anything written in the statement, you should speak to your named contact at the LEA as soon as possible.

You can also get advice from the Special Educational Needs & Disability Information,

Caring for children with heart conditions

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Advice and Support Service –
SENDIASS, IPSEA (see contact details
at the end), or appeal to the SEN
Tribunal.

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0300 561 0065

The LEA will review your child's EHCP annually, checking your child's progress and making sure the EHC Plan continues to meet their needs. If your child is 0-5 years, the EHCP will be reviewed every six months.

Building a partnership with the school

Forming a strong partnership with the school is central to getting the right support for your child. By creating a close relationship with the school, you can work together to help them plan appropriate support or other activities for your child.

It is important to give the school as much information about your child's heart condition as possible. You can also ask your child's cardiac liaison nurse (CLN) to speak to the school. CLNs are trained to advise teachers on meeting your child's needs and are also normally able to reassure them about any concerns they have.

For support with getting a statement, you may want to ask the head teacher or other relevant professionals to write a letter that supports your application. You can also get advice from IPSEA (Independent Panel for Special Education Advice) on **0800 0184016**

Moving up to secondary school

Your child's primary school will send any documents related to your child's special educational needs, including their EHC Plan, if they have one, to the secondary school directly.

About this document:

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**To inform CHF of a comment or suggestion,
please contact us via info@chfed.org.uk or Tel:**

Information sheet



Useful contacts and more information

You may also want to have a look at our fact sheet 'Information for teachers'. Order it on our infoline **0300 561 0065** or download it from our website **www.chfed.org.uk**.

Download NHS England's Special Educational Needs and Disabilities (**SEND**) **Quick Guides**.

These are:

- Guidance for health services for children and young people with Special Educational Needs and Disability (SEND)
- Commissioning for transition to adult services for young people with Special Educational Needs and Disability (SEND)

Both of these aim to assist health commissioners and providers with joint commissioning of services and provide guidance on developing processes to ensure that children and young people with SEND are fully supported.

The Quick Guides link:

<https://bit.ly/2vvV6Bo>

Also find out more about the **Children's Rights Alliance for England** briefing on mental health (Using children's rights in mental health policy and practice).

Further information:

<https://bit.ly/2MuttDq>

Visit **SENDIASS**, the Special Educational Needs and Disability Information Advice and Support Service at www.kids.org.uk/sendiaass. This is a free, confidential and impartial service for parents, carers, children and young people (up to 25 years) on a range of SEN support including local policy and SEN disability law from independently trained staff and advice for parents, carers and young people on interpreting and understanding information regarding their own situation.

IPSEA Independent Parental Special Education Advice Phone: 0800 018 4016
Website: www.ipsea.org.uk

Special Educational Needs & Disability Tribunal (**SENDIST**) SEN helpline: 01325 289 350
Website: www.sendist.gov.uk
Email: sendistqueries@hmcts.gsi.gov.uk

The National Association for Special Educational Needs (**NASEN**) promotes the education, training, and development of all those with special educational needs.
Website: www.nasen.org.uk

MedicAlert – 01908 951 045

Many parents have found a MedicAlert bracelet useful for getting suitable care in an emergency.

Children's Heart Federation is a Registered Charity No. 1120557 and a Registered Company by guarantee in England and Wales No. 6329763

Website: www.medicalert.org.uk

Useful websites:

- ace-ed.org.uk– ACE Education Advice and ACE Education Training
- ndti.org.uk– Preparing for Adulthood
- councilfordisabledchildren.org.uk– Council for Disabled Children
- gov.uk/government/organisations/ofsted– Recent Ofsted reports
- gov.uk– Government Website

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