



Courage Hope Inspiration

Additional Support at School

Most children and young people living with Hyperinsulinism can attend mainstream schools and for many, have made long-lasting friendships, developed their independence and confidence, as well as enjoyed academic success from their time at school and beyond.

There are three levels of support available at school for your child or young person:

- **Individual Health Care Plan (IHCP)** – a plan outlining the type and dose of medication or treatment your child or young person may require during the school day.
- **Special Educational Needs (SEN) support** (which mainstream state schools must provide) – additional support provided by the school for a child or young person with a disability.
- **Education, Health and Care (EHC) Plan** (sometimes called an EHCP) – for when SEND support provided by the school is not enough for your child or young person to get the support they need.

The level of support that your child or young person requires is dependent on how their Hyperinsulinism impacts them and their learning.

Individual Health Care Plans (IHCPs)

If your child or young person needs medication or treatment during the school day, this should be documented in an Individual Health Care plan (IHCP). This plan can include information such as when to give their main medication for blood glucose control such as Diazoxide, hypoglycaemia treatments such as glucogel, or indeed normal medications such as regular pain relief, antibiotics etc. The plan will also state what dosage and what times these will need administering.

It is important that schools know when intervention may be required, so an IHCP will also need to incorporate the care plan from the child's medical team as well as their hypo plan. This is particularly important for younger children who may be unable to express themselves clearly.

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Individual Health Care Plans (IHCPs) - continued

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Individual Health Care Plans are developed in partnership between the school, parents, pupils, and the relevant healthcare professional who can advise on a child or young person's case. Your child's school may not call it an IHCP, but the governing body must ensure that arrangements are in place to support pupils with medical conditions.

The aim of an IHCP is to ensure that schools know how to support your child or young person effectively and to provide clarity about what needs to be done, when and by whom. Specifically for children and young people living with Hyperinsulinism, this plan should include a clear protocol for agreeing what will happen if the child or young person is having several hypoglycaemic episodes throughout the day which staff are unable to stabilise. The child's hypo plan will give clear guidance on how to manage hypoglycaemic episodes and when emergency intervention, such as calling 999, is required.

Steps to take to create an IHCP with your child's school

- Inform the school that your child or young person has Hyperinsulinism.
- Signpost the school to The Children's Hyperinsulinism Charity's website (www.hyperinsulinism.co.uk) to help explain what Hyperinsulinism is and the impact it can have on your child or young person.
- Request an IHCP for your child or young person so that they have the relevant support at school.
- School staff should arrange a meeting to discuss your child or young person's situation and needs and agree an IHCP.
- The school should identify any training needs for staff such as blood glucose monitoring, medication/injection administration, use of a gastrostomy and feeding pump etc. The parents and child may wish to be present to support the school with any training (e.g. how to take a blood glucose test, using a feeding pump).
- Agree a follow-up meeting with the school to review the training needs and identify what is and is not working well according to the IHCP.
- Review the IHCP annually or when a child or young person's needs change. Before the end of the summer term or at the start of a new school year is a good time to review with the new class teacher and other new school staff.

Education and Health Care Plans (EHCPs)

The EHCP is a legal document that sets out the education, healthcare and social care needs of a child or young person for whom extra support is needed in school, beyond that which the school can provide. The special educational provision described in an EHCP plan must be provided by the child or young person's local authority (LA). The EHCP was formerly known as a 'statement of special educational needs'.

Children with an EHCP may be entitled to extra one-to-one support in school (though not necessarily full-time) and will have outside agencies involved in their support (e.g. physiotherapists, behavioural experts, speech and language therapists or sensory impairment teachers). The EHCP can also give parents and young people more choice about which school or other setting the child or young person can attend.

An EHCP plan can only be issued after a child or young person has gone through the process of an Education, Health and Care needs assessment.

An EHCP is for any child or young person that has a significant and complex Special Educational Need or Disability (SEND) and is required when a child or young person's needs cannot be met by the usual support that is available to them in their school or setting.

Many children and young people with SEND receive support in their school or setting without an EHCP; however, their support would come from resources already available within school, which is called SEN support. Following SEN support, some children or young person's needs may be deemed significant and complex and, therefore, require an EHC assessment by the Local Authority.

Many children and young people living with moderate to severe Hyperinsulinism have an EHCP to support them through mainstream education. Some of the support provided includes training for the school staff, one-to-one support for the child (e.g. supervision at lunchtimes, through the school day to keep the child safe) and aids and equipment. Some children and young people living with Hyperinsulinism also have other conditions and the combined needs are significant to qualify for additional help in an EHCP.

An EHCP should provide support from birth up to the age of 25 to support with further education, training, and support into the workplace.

If a young person is in or beyond Year 9, the EHCP must set out the provision to support the young person in preparing for adulthood and independent living.

Parents/Carers can contact the school directly to request an EHC plan or their LA to ask for an EHC assessment for their child or young person. At this point, the LA will review all evidence on a panel and decide on whether to assess your child or young person. If a decision is made to assess, at the end of that assessment period the LA will decide whether to issue an EHCP. Enclosed is a template to refer to.

Appealing a Decision

When the LA makes certain decisions about the education and/or training of a child or young person with SEN, there is a right of appeal to the First-tier Tribunal (SEND Tribunal).

To be able to appeal, you must be a parent or a young person over the age of 16. In education law 'parent' means you are either a birth parent, have acquired parental responsibility or have care of the child (e.g. a foster parent or grandparent with whom the child lives).

If the decision concerns a child, it is the parent who has the right of appeal. If the decision concerns a young person, then it is the young person who has the right of appeal.

When can I appeal?

You can bring an appeal to the SEND Tribunal if an LA:

- refuses to carry out an EHC needs assessment or a re-assessment
- refuses to issue an EHCP
- issues or amends an EHCP but you disagree with any or all of Section B (special educational needs), Section F (special educational provision) or Section I (placement)
- decides not to amend an EHCP after an annual review
- decides to cease to maintain the EHCP at any point.

From April 2018, parents and young people have the right to appeal against the health and social care sections of the plan (Sections C, D, G and H).

Enclosed is a template letter you may wish to refer to if you want to request a reassessment or appeal against a decision.

Visit the IPSEA website (www.ipsea.org.uk) for more information, including information on how to change an EHCP and appealing to the SEND tribunal.

Special Educational Needs (SEND) Support

Section 20 of the Children and Families Act 2014 says a child has Special Educational Needs (SEND) if: “they have a learning difficulty or disability which calls for special educational provision to be made for him or her”.

If you are unsure whether your child or young person qualifies for SEND support, consider the following two questions:

1. Does my child with Hyperinsulinism have a learning difficulty or disability?

Someone has a disability if they have a physical or mental impairment which has a substantial and long-term adverse effect on their ability to carry out day-to-day activities.

A child or young person has a learning difficulty or disability if:

- they have significantly greater difficulty in learning than the majority of others of the same age, or
- they have a disability which makes it difficult for them to use the facilities normally provided for others of the same age in mainstream schools or post-16 institutions.

For children with Hyperinsulinism, this may look like when they cannot keep up with writing in lessons, retaining information etc due to hypoglycaemic episodes which have caused brain damage; if they are in pain or suffering fatigue and cannot concentrate in lessons or have to stay at home; or if they need adaptations such as padded ergonomic chairs and soft grip pencils. Many children with mild to moderate Hyperinsulinism may need additional support through SEN provision.

2. Does that learning difficulty or disability call for special educational provision to be made?

Special educational provision is any educational or training provision that is additional to, or different from, that which is made generally for other children or young people of the same age. This is a wide definition and could cover a wide range of things.

For example, for children or young people with Hyperinsulinism:

- needing one-to-one support for various needs
- sessions with a physiotherapist and training for teachers
- adaptations at home and school to make personal care easier
- having materials provided in a larger font
- a laptop with voice recognition software and individual support on how to use it

SEND support is available at all levels of education, from nursery to further education. The school may identify your child or young person's special educational needs. Legally, they must contact you about what support is available. Your GP or another professional may also refer your child for support.

You can ask for SEND support when your child:

- starts a new school or nursery
- is already at school or nursery

You should be involved throughout the SEND process and receive updates; young people aged 16 to 25 will also have a say in their support.

The first person to talk to about your child or young person's needs is the headteacher and the Special Educational Needs Co-ordinator (SENCO). All schools have a SENCO. It is the SENCO's job to work with teachers, parents, and health professionals to meet pupils' special educational needs.

Ask for an appointment with the SENCO. Explain why your child needs extra support. If the school is unaware of your child's needs, check the school's SEND policy and ask for a SEND assessment.

Children under 5

SEN support for children under 5 includes:

- a written progress check when your child is 2 years old
- a health visitor carrying out a health check for your child if they are aged 2 to 3
- a written assessment in the summer term of your child's first year of primary school making reasonable adjustments for disabled children, such as providing aids (e.g. tactile signs)

Nurseries, playgroups, and childminders registered with Ofsted follow the Early Years Foundation Stage (EYFS) framework. The framework makes sure that there is support in place for children with Special Educational Needs and Disability (SEND).

Talk to a doctor or health adviser if you think your child has SEND but they do not go to a nursery, playgroup, or childminder. They will tell you what support options are available.

Children between 5 and 15

Talk to the teacher or SENCO if you think your child needs:

- a special learning programme
- extra help from a teacher or assistant
- to work in a smaller group
- observation in class or at break
- help taking part in class activities

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- extra encouragement in their learning (e.g. to ask questions or to try something they find difficult)
- help communicating with other children
- support with physical or personal care difficulties (e.g. eating, getting around school safely or using the toilet)

Young people aged 16 or over in further education

Contact the college before your child or young person starts further education to make sure that they can meet your child's needs. The college and your local authority will talk to your child about the support they need.

Further information and guidance can be found by visiting:

<https://www.gov.uk/children-with-special-educational-needs/special-educational-needs-support>

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/803956/supporting-pupils-at-school-with-medical-conditions.pdf

<https://www.ipsea.org.uk/pages/category/education-health-and-care-plans>

Timeline for applying for a school place:

Applications open on different days in each council area. Apply online or by using your council's application form. Closing date for applications for Secondary schools is the end of October and for Primary schools, January. Please check with your Local Authority for exact dates.

Confirmation of places for secondary schools are sent out in the March and primary places, April.

If you need to apply for an EHCP, start the process in plenty of time (January before September start as an example). The whole process can take around 20 weeks and therefore it is crucial to apply as soon as possible to make the process less daunting. If your child is in Nursery or you have assistance from Portage, they can help start the ball rolling.

For IHCP's, start liaising with the school as soon as you have been notified of your child's placement.

Once you have confirmation of your child's school, liaise with headteacher/senco to arrange discussions about your child's needs, school and family packs from The Children's Hyperinsulinism Charity, staff training etc.