

MANAGING HYPERINSULINISM IN SCHOOL



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OBJECTIVES

- Preparing for school
 - Child
 - Parents
 - Schools
 - Medical team
- Resources
- Support
- Educational Health Care Plans (EHCP)
- Summary



AS PARENTS.....



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STARTING SCHOOL

- Transition of care: Starting Primary/secondary
- Child, Parent and school anxiety
- Early preparation and organisation is key



- Increased independence around care
- Disclosure of medical needs to new friends
- Managing a difference that is not always visible.
- Same opportunities as other children
- Enjoyable and safe environment
- Reach their full potential



PARENTS

- Challenges: trust, right support, handing over care
- Meet with school to discuss and provide information about medical/ educational
- Good communication
 - Book appointment
 - Communication book
- Provide all essential equipment and ensure always well stocked
 - Medications
 - Hypo plan and emergency contact details
 - Glucometer - Strips and lancet
 - Hypo treatment -glucogel, snacks (Hypobox)

- Schools must make reasonable adjustments to ensure that children and young people with disability including those with medical needs are not put at a substantial disadvantage compared with their peers
- Enough staff trained by healthcare professional so that a child with a medical condition can take part in all aspects of school life
- Contingency plans must be in place if all staff leave
- No legal duty that requires school staff to administer medicines

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- Join the family on their journey - smooth communication, working collaboratively and co-ordinating care
- HI management complicated
- Liaison with other services
- Best position to provide education, training and ongoing support



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- Work closely with school and community nurses in educating and supporting school staff.
 - Blood glucose monitoring
 - Recognising a hypoglycaemic episode
 - Management of a hypoglycaemic episode
 - Administration of medications
 - Feeding plans and enteral feeding support
 - Support with Care plans, EHCP application

Low Blood Sugar Symptoms



HYPOGLYCAEMIC PLAN FOR

- 1.If blood glucose level is 3.5mmols or less, re-check after 10mins on an alternative site.
- 2.If his blood glucose level is still 3.5mmols or less, then give her 1/2 tube of glucogel and a snack and drink.
- 3.Re-check his blood glucose level 10 minutes later. To ensure blood glucose has risen.
- 4.If continues to be hypoglycaemic and does not respond to glucogel and a snack and drink then please repeat step 2 and take him to the nearest hospital for further management (Call an ambulance). This may include insertion of an intravenous cannula and intravenous 10% glucose to stabilize blood glucose levels especially when he is unwell and unable to tolerate food.
- 5.If presents to hospital with a hypoglycaemic episode he should always be admitted to have his blood glucose levels monitored and correction of hypoglycaemia with intravenous glucose.

HYPO TREATMENT

Product	Age of patient	Recommended hypo management (glucose in gram)
Glucogel (10g of glucose in each tube)	Neonate - 6 months	1/3 tube 3.33g
	6 months - 2 years	1/2 tube 5g
	2-5 years	1 whole tube 10g
Lift (previously Glucojuice) (15g of glucose in 60mLs)	5 years and over	1 1/2 tube 15g
	2-5 years	40mLs (10g)
Glucose tablets (4g of glucose)	5 years and over	60mLs (15g)
	2 -5 years	2 1/2 tabs (10g)
	5 years and over	4 tabs (16g)





Great Ormond Street Hospital for Children NHS Foundation Trust: Information for nurseries, schools and colleges

Congenital hyperinsulinism

One of your pupils has a condition called congenital hyperinsulinism, which is present at birth and causes high levels of insulin to be produced. This information sheet from Great Ormond Street Hospital (GOSH) explains about congenital hyperinsulinism and the signs and symptoms of a hypoglycaemic episode where the blood glucose levels fall too low. It also contains guidance for managing hypoglycaemic episodes in the nursery, school or college setting.

If you would like further information about congenital hyperinsulinism or have any questions, please contact the Clinical Nurse Specialists (CNS) for Congenital Hyperinsulinism on 020 7405 9200 ext. 9360 or bleep 1016. You can also email them at cn.hypoglycaemia@gosh.nhs.uk

What is congenital hyperinsulinism?

Congenital hyperinsulinism is characterized by inappropriate and unregulated insulin secretion from the beta-cells of the pancreas. In CHI, the beta-cells release insulin inappropriately all the time and insulin secretion is not regulated by the blood glucose level (as occurs normally).

Normally, the beta-cells release insulin in response to the level of glucose in the blood. Insulin converts the glucose into a form that can be used by the body. If too much glucose is converted, it is stored in the liver and muscles as glycogen. Glycogen can be converted back to glucose to be used when glucose is not available.

In CHI, too much insulin causes the blood glucose level to drop too low. High insulin levels prevent ketone bodies being made. This means that the brain is not only deprived of its most important fuel (glucose), but also ketone bodies which are used as alternative fuels. When the brain has no glucose or ketones to use as fuel then the child is at risk of seizures, loss of consciousness and even brain injury.

How is congenital hyperinsulinism treated?

Treatment aims to keep a child's blood glucose level stable at 3.5mmol/litre to 10mmol/litre. This can be managed by regular high carbohydrate feeds alongside medicines to reduce insulin secretion. Sometimes the management of CHI can be complicated. However, once CHI is stable, a degree of normal life can be achieved. Brain function in CHI can be normal if hypoglycaemia has been diagnosed and treated quickly, but can be very variable depending on the amount of damage caused before diagnosis and treatment.

Medication

Your pupil may need to take their medication at regular intervals throughout the school day as shown in the table below. If the dosage or dose schedule changes as your pupil grows older, we will update this page.

Medicine name	Dose	Dosage times			
		AM	AM	PM	PM
<input type="checkbox"/> Diazoxide					
<input type="checkbox"/> Chlorothiazide					
<input type="checkbox"/> Octreotide					
<input type="checkbox"/> Sirolimus					
<input type="checkbox"/> Other medications					

Food and drink

An important part of treating CHI is to ensure that your pupil has regular and frequent snacks and drinks throughout the school day. These will be provided by your pupil's family and should be carried with them at all times. Please allow them to leave lessons to have a snack or drink if needed. Each day, your pupil should have the following snacks and drinks.

Snack or drink	Times			
	AM	AM	PM	PM

Blood glucose monitoring

Your pupil will also need to check their blood glucose levels at regular intervals throughout the day. Please allow them to leave lessons to do this if needed. Children and young people are given a blood glucose monitor which measures the amount of glucose in the blood. This is done by a small finger prick that will give a single drop of blood to put on a strip. The monitor will display the blood glucose level as a figure measured in mmol/litre.

Blood glucose monitoring should be done at the following times:

AM	AM	PM	PM

Additional checks may be needed if your pupil is unwell or takes part in energetic activities such as games and school trips. Please liaise with the pupil's family about additional blood glucose monitoring.

Signs and symptoms of hypoglycaemia

A hypoglycaemic episode will occur when blood glucose is less than 3.5mmol/litre. Some children also notice they don't feel right when their blood sugar levels start to go too low. Common symptoms include:

- Feeling tired or sleepy
- Feeling wobbly or shaky
- Feeling dizzy
- Feeling hungry
- Feeling grumpy or angry
- Having a headache

Your pupil may also show the following symptoms:

If you notice any of these signs, or your pupil is exhibiting unusual behaviour, you should check their blood glucose level immediately and follow the emergency plan below.

Treating a hypoglycaemic episode

Your pupil will carry an emergency Glucogel®/snack with them at all times to deal with a hypoglycaemic episode. If one occurs, inform the family immediately so that, not only are they aware, but they can restock the Glucogel®/snack if required.

- If the blood glucose level is 3.5mmol/litre or lower, recheck using a new finger prick and testing strip
- If the blood glucose level is still 3.5mmol/litre or lower, give them half a tube of Glucogel® and a snack

- Recheck their blood glucose level 10 minutes later using a new finger prick and testing strip
- If their blood glucose level remains at 3.5mmol/litre or lower or they are not responding to the Glucogel® and snack, give them the remaining half of the Glucogel® tube and dial 999 to call an ambulance.

More information about CHI can be found at www.gosh.nhs.uk/medical-information/clinical-specialties/endocrinology-information-for-parents-and-visitors/conditions-we-treat/congenital-hyperinsulinism

RESOURCES



Great Ormond Street Hospital for Children NHS Foundation Trust: Information for Families

Diazoxide and chlorothiazide suspensions

This information sheet should be read in conjunction with any patient information leaflet provided by the manufacturer.

This information describes diazoxide and chlorothiazide suspensions, which are usually prescribed together. It explains how they are given and some of their side effects. Each person reacts differently to medicines so your child will not necessarily suffer every side effect mentioned. If you have any questions or concerns, please ask your doctor, nurse or pharmacist or telephone one of the contact numbers on the information sheet.

What are diazoxide and chlorothiazide?

Diazoxide is used to treat persistently low blood sugar levels (hypoglycaemia) caused by the body producing too much insulin (hyperinsulinism). It works by blocking the release of insulin by the body.

Chlorothiazide is a diuretic, that is, a medicine that increases the amount of urine produced by the kidneys. It is used in conditions where the body retains too much fluid, causing puffiness (oedema) especially around the eyes or affecting the hands or feet. Chlorothiazide is commonly prescribed alongside diazoxide, as a side effect of this medicine is fluid retention.

How are they given?

Diazoxide suspension is given by mouth two or three times a day. Chlorothiazide suspension is usually given twice a day. For guidance on how to give your child liquid medicines, please read our information sheet or watch our video podcast available on our website at www.gosh.nhs.uk/gosh_families/information_sheets/medicines_liquid/medicines_liquid_families.html

Diazoxide and chlorothiazide suspensions are not readily available from your community pharmacy. Neither medicine is available in the UK and so has to be imported from abroad by a licensed pharmaceutical import company. Supplies of these medicines may take longer than usual to obtain, usually several days.



Sheet 1 of 3

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Congenital Hyperinsulinism (CHI)

Welcome to the homepage for Congenital Hyperinsulinism (CHI) at Great Ormond Street Hospital.

Congenital hyperinsulinism (CHI) is a very complex medical condition that presents with severe hypoglycaemia (low blood glucose) in the neonatal, infancy and childhood period. The congenital hyperinsulinism centre at Great Ormond Street Children's Hospital NHS Trust has treated over 500 patients and is a national and international referral centre for patients from as far as India and Malaysia.

We have a dedicated and committed multidisciplinary team to deliver the best care possible to these highly complicated patients. Combined with our high class clinical service we have developed cutting edge translational research to understand the genetic basis of congenital hyperinsulinism.

Introduction to CHI	Video	Meet our team
Further information about what is Congenital Hyperinsulinism	Our video outlines the mechanism of Congenital Hyperinsulinism.	Learn more about the different roles within the CHI team .
HI Fund	Patient stories	Contact us
How you can make a difference to Children's Hyperinsulinism UK	Parents of GOSH patients share their experiences of hyperinsulinism.	Details on how to contact the CHI team at Great Ormond Street Hospital.



Great Ormond Street Hospital for Children NHS Foundation Trust: Information for Families

Octreotide injections

This information sheet should be read in conjunction with any patient information leaflet provided by the manufacturer.

This information describes octreotide injections, how they are given and some of its side effects. Each person reacts differently to medicines so your child will not necessarily suffer every side effect mentioned. If you have any questions or concerns, please ask your doctor, nurse or pharmacist or telephone one of the contact numbers on the information sheet.

What is octreotide?

Octreotide is used to treat persistently low blood sugar levels (hypoglycaemia) caused by the body producing too much insulin (hyperinsulinism). It is a manmade version of the natural hormone, somatostatin, which stops certain cells in the pancreas releasing insulin. It can be used alone or together with the medicines diazoxide and chlorothiazide as directed by your child's doctor.

The use of octreotide in children is not currently licensed in the UK. Medicines are often used outside of their license (off-label) in children because trial data is not available for a specific use. This is not necessarily hazardous but should be explained and agreed before use. Your doctor will explain this further to you. Octreotide for injection is available as different strengths, which can be injected

under the skin (subcutaneously). At GOSH, we use a multi-dose vial, which can be used for up to 10 injections. The strength of this injection solution is 1mg of active ingredient in 5ml of liquid. The solution also contains water and preservatives.

How is it given?

Octreotide is given as a subcutaneous injection, three to four times a day. The dose should be calculated in millilitres, drawn up from the multi-dose vial and given using a BD insulin syringe. You will have been taught how to give subcutaneous injections before leaving hospital but please read our information sheet available on our website at http://www.gosh.nhs.uk/gosh_families/information_sheets/medicines_subcutaneous_injections/medicines_subcutaneous_injections_families.html

Who should not use octreotide injections?

People with the following conditions should discuss taking these medicines with their doctor.

- Hypersensitivity to octreotide or any of its ingredients
- Pregnant, could be pregnant, trying to become pregnant or breastfeeding



Sheet 1 of 2

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<https://www.gosh.nhs.uk/medical-information/clinical-specialties/endocrinology-information-parents-and-visitors/conditions-we-treat/congenital-hyperinsulinism-chi>

SUPPORT

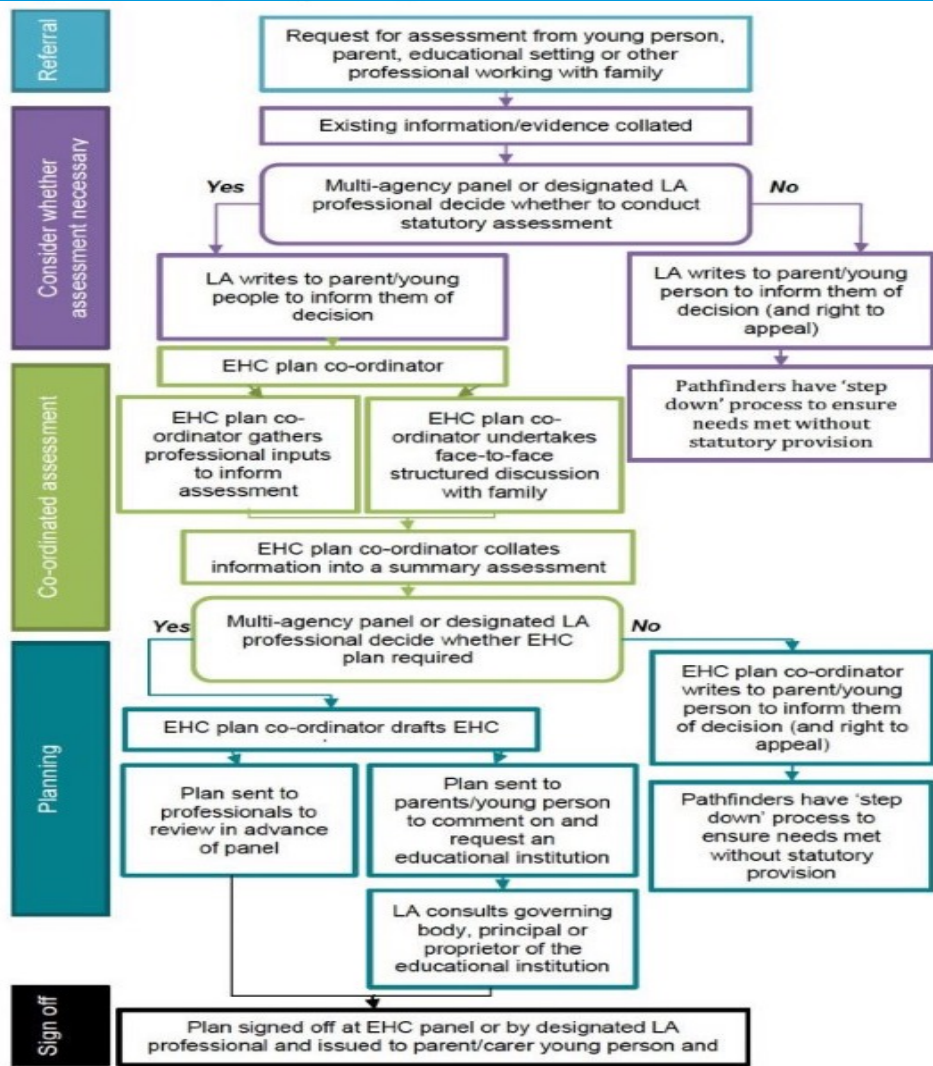
- Children and their families living with a health condition have an increased chance of experiencing psychological difficulties
- Some children with HI do present with sustained attention and memory issues
- This is not true for all children and families and does not mean everyone will experience these challenges
- It is important to notice and acknowledge when some more support may be helpful
- Psychology input can help a child or young person think about the non medical elements of their identity

WHAT TO DO?

- Ensure teacher is aware of child's cognitive strengths and weaknesses
- Identify and discuss any issues/concerns with teachers and SENCO
- Discuss support required at school/home and implement interventions and strategies
- Referral to paediatrician/ psychologist for further assessment
- Contact local authority - EHCP application (England)
- Support groups

EDUCATIONAL HEALTH CARE PLAN

- Designed to create a real change in the way that education, health and social care professionals work with families and young people
- Children, young adults from 0-25yrs
- Educational needs require more help, normally provided in a mainstream education
- Compiled by local authority with input from education, health and social care professionals
- Legal document that describes a child or young person's special educational, health and social care needs.
- Must be reviewed at least once a year and remains in place until child leaves education or the local authority decides the plan is no longer needed to help in their education.
- If move to another local authority the plan will be transferred.



- Educational Health Care Plan application process takes approximately 20 weeks from date of assessment
- Appeal process if application unsuccessful

MULTIDISCIPLINARY TEAM



Child and family



Psychology

Social Work

Dietician

Play specialist

Pharmacy

G.P

Local hospital



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SUMMARY

- HI is not a familiar condition to general population
- Education and support for child, parents and schools is essential
- Discuss any concerns to ensure early intervention and support
- Future
 - Study days
 - Virtual teaching
 - Videos
 - E-Learning

**It is absolutely possible to live well with HI and
for every child to reach their full potential**

CONTACT DETAILS

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NHS Foundation Trust



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THANKYOU

- Children, young people and families
- Schools and nurseries
- Community and school nurses
- UK and International support groups
- HI/endocrine team at GOSH
- HI colleagues from other centres



QUESTIONS



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