

# Congenital hyperinsulinism: information for nurseries, schools and colleges

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One of your pupils has a condition called congenital hyperinsulinism which is present since 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 for Congenital Hyperinsulinism on 020 7405 9200 extension 0360 or email them at [cns.hypoglycaemia@gosh.nhs.uk](mailto:cns.hypoglycaemia@gosh.nhs.uk)

Congenital hyperinsulinism (CHI) 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. However, children and young people with CHI may have issues with brain development causing memory and processing information so may need additional support.

## 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 glucose product or 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 glucose product or 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 glucose product 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 glucose product and snack, give them the remaining half of the glucose product tube and dial 999 to call an ambulance.

## Glucose products guidance

Glucose gel tube containing 10g glucose

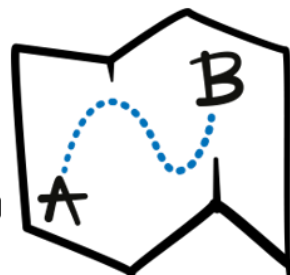
- Up to six months of age – give  $\frac{1}{3}$  tube = 3.33g
- Six months to two years – give  $\frac{1}{2}$  tube = 5g
- Two to five years – give 1 tube = 10g
- Five years and older – give  $1\frac{1}{2}$  tubes = 15g

Glucojuice® 60mLs contains 15g glucose

- Two to five years – give 40mLs = 10g
- Five years and older – give 60mLs = 15g

Glucose tablets – each tablet contains 4g glucose

- Two to five years - give  $2\frac{1}{2}$  tablets = 10g
- Five years or older - give 4 tablets = 16g



## 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 change as your pupil grows older, we will update this page.

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

## 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 drinks	Times			
	AM	PM	AM	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
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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.

