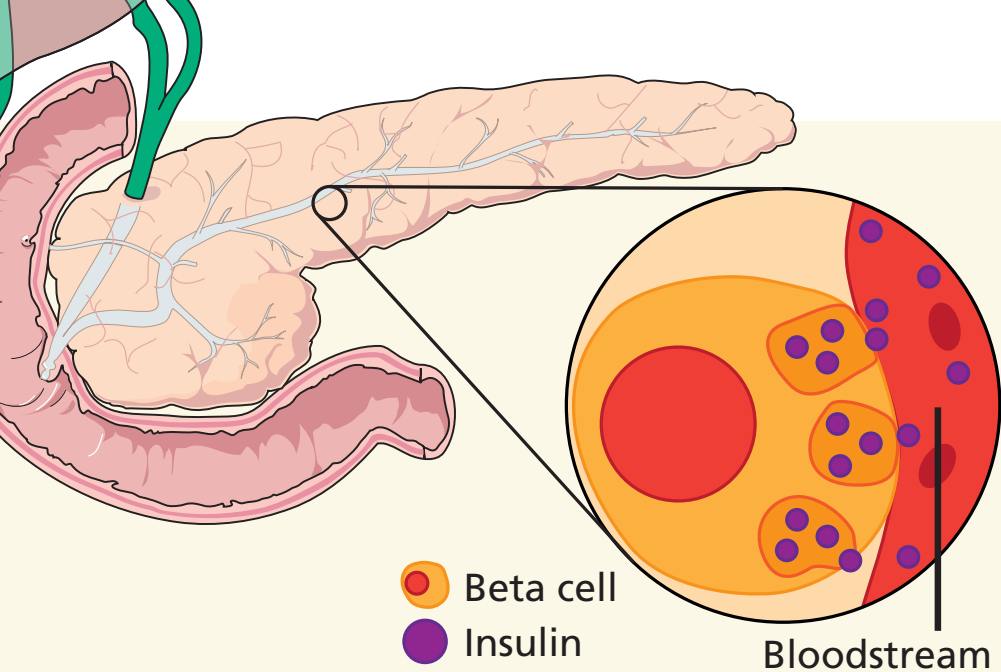


Congenital Hyperinsulinism



Information for children & young people

Great Ormond Street Hospital for Children NHS Foundation Trust



What is Congenital Hyperinsulinism?

- 'Congenital' means something that you were born with
- 'Hyper' means too much
- 'Insulin' is a hormone (chemical messenger)

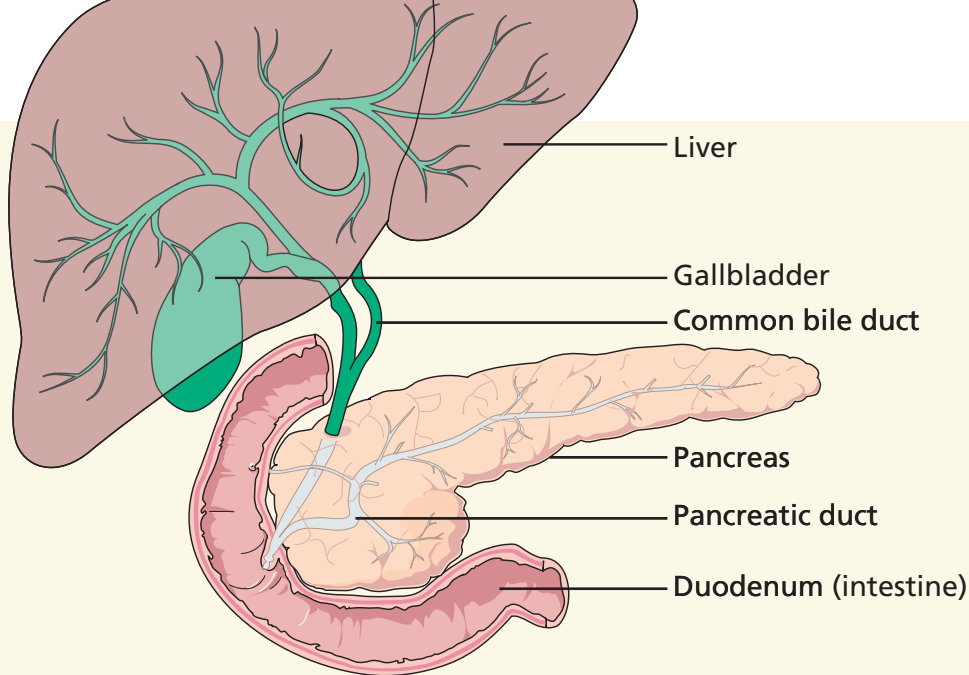
Congenital Hyperinsulinism means that there is too much insulin in your body. Because it is such a long word some of the doctors and nurses shorten it to CHI, so let's do the same.

What is Insulin?

'Insulin' is a special hormone. A hormone is a chemical messenger that travels around your body and tells it how to work.

Insulin is released by our pancreas. The pancreas is a gland (a special type of organ) that hides behind our stomach. The pancreas also helps us break down and digest the food that we eat.

If our blood sugar levels are too high (often after eating, especially food with lots of sugar) our pancreas should release insulin to tell our body to lower the amount of sugar in our blood. This is to make the blood sugar level just right.



What happens in Congenital Hyperinsulinism (CHI)?

Unfortunately in CHI your pancreas makes and releases insulin continuously even when it does not need to. This can make your blood sugar levels go too low, which can be dangerous if not treated quickly. The doctors and nurses call this hypoglycaemia.

- 'Hypo' means too low
- 'Glycaemia' means glucose (or sugar) in the blood

So, hypoglycaemia means 'low blood sugars'

Both our brain and body need **just the right amount** of sugar to keep healthy. Not too little, not too much. Our brain especially needs sugar to keep it working. Sugar is like the fuel for the brain. It gives us 'brain power' and helps us think and learn new things. If our blood sugar levels are too low, our brain will not work very well.

It is important to keep your blood sugar level **above 3.5 mmol/l** at all times to make sure your brain gets all the fuel it needs.

How do I know if my blood sugar levels are okay?

You should have a blood glucose monitor which measures the amount of sugar in your blood. This is done by a small prick, usually on your finger, that will give a single drop of blood to put on a strip. Check the number on the monitor to see if your blood sugar levels are just right!

Some children notice they don't feel right when their blood sugar levels start to go too low. Tick the changes that happen in your body. They are different for everybody.

My Symptoms of Low Blood Sugar Levels are:

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

If you have any of these symptoms you can use your monitor to double check. If the monitor says **under 3.5** get a grown up to help you straight away. The grown up will give you something sugary to eat or drink.

Warning: Sometimes when your blood sugar levels go too low (under 3.5 mmol/l), your brain can stop working properly and you may not notice that things are wrong!

Sometimes it is important to test your blood sugar levels regularly to make sure they are okay. Write in the box when or how often the doctor or nurse tells you that you should check your blood sugar levels.

I need to check my Blood Sugar Levels...

How can Congenital Hyperinsulinism (CHI) be treated?

Medications

There are different medications that can stop your pancreas releasing too much insulin. Tick the medication that you take. Remember everybody is different, and medicines work differently on different people.

The medications that I take are:

- ☐ **Diazoxide:** I take this ____ times per day. This helps keep my blood sugar levels at just the right level for my brain and body to work
- ☐ **Chlorothiazide:** I take this ____ times per day. This stops my body becoming puffy if it holds too much water (this can happen when you take Diazoxide).
- ☐ **Octreotide Injection:** I have this ____ times per day. This helps keep my blood sugar levels at just the right level for my brain and body to work
- ☐ **Creon:** I take this ____ times per day. This helps my body break down and digest the food that I eat.
- ☐ **Emergency Glucose:** I take this if my blood sugar levels have gone too low and I need to get them back to a safe level quickly
- ☐ Other _____

Operation

Sometimes if your CHI was really serious, part of your pancreas may have had to be removed. If this happened to you, it probably happened when you were a baby and you may have a small scar to show for it. This operation is called a 'pancreatectomy'. Sometimes you still need to take medication for your CHI even if you have had this operation.

Diet

If you have CHI it is very important to eat healthily. This means three meals a day (especially breakfast) and lots of healthy snacks in between meals. Eating is another important way to give our brain and body the 'fuel' it needs.

Because your body has a blood sugar problem, it is important **not** to have too much sugar. But sometimes a grown up will give you sugary food or drink if your blood sugar levels go too low.

Notes

If you have any other questions or want to learn more about your CHI,
you can call the Clinical Nurse Specialist in Hypoglycaemia
at Great Ormond Street Hospital 020 7405 9200 on extension 0360

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