





# Managing episodes of low blood sugar for children with ketotic hypoglycaemia

Children's Metabolic Service

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This booklet provides information and advice for schools and childcare settings about ketotic hypoglycaemia.

Children with ketotic hypoglycaemia are under the Metabolic Team at the Leicester Royal Infirmary. Please contact the Metabolic Specialist Nurse if you have any questions (see p4 for details)

## What is ketotic hypoglycaemia?

Ketotic hypoglycaemia is a condition that most commonly affects young children. This illness causes a low blood sugar (hypoglycaemia) and a build-up of ketones in the body's tissues and fluids (ketosis). Ketones are chemicals made when supplies of sugar to the body are low and the body must break down fat for energy.

Children are usually diagnosed after an episode or multiple episodes of unexplained low blood sugar (hypoglycaemia) during periods of illness or prolonged fasting. Children that have episodes of ketotic hypoglycaemia usually 'grow out' of the tendency to have low blood sugars at around school age.

Children with ketotic hypoglycaemia lead healthy and active lives and it should not cause the child any problems when they are well and eating normally. However, when unwell, children with ketotic hypoglycaemia have a tendency to have a low blood sugar level. The child will have a plan for illness that will reduce the risk of them having low blood sugar.

# How is ketotic hypoglycaemia managed?

Children with ketotic hypoglycaemia are well and eating as normal there is no reason for them to have a low blood sugar. However, if a child with ketotic hypoglycaemia fasts for too long or becomes unwell, for example, with high temperature or being sick (vomiting), they

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could have a low blood sugar.

# Symptoms of low blood sugar

While each child may have symptoms of low blood sugar differently, the most common include:

- Shakiness and dizziness.
- Sweating.
- Hunger.
- Headache.
- Irritability.
- Pale skin colour.
- Sudden moodiness or behavioural changes, such as crying for no apparent reason.
- Clumsy or jerky movements.
- Difficulty paying attention, or confusion.

## **Emergency regime (ER)**

To prevent a low blood sugar it is important for children with ketotic hypoglycaemia to start their oral **emergency regime** (ER) when needed.

The emergency regime (ER) involves the child drinking a short-acting sugar (carbohydrate) drink. The ER drink provides the child's body with the energy it needs quickly to prevent a low blood sugar.

Each child with ketotic hypoglycaemia will have their own ER drink for times when they are unwell. The ER drink will contain sugar (carbohydrate) and the concentration of carbohydrate needed will increase as the child gets older (see table below).

Age	ER drink (1 sachet made up to 200mls of water)
0-1 year	SOS 10
1-2 Years	SOS 15
2-10 Years	SOS 20
10 Years+	SOS 25

Parents will be responsible for leaving an in date supply of their child's ER at the school/nursery setting.

## If the child is unwell at school or nursery.

**Step 1**: Contact parents immediately if the child is unwell for example, being sick (vomiting), tiredness (lethargy), high temperature or you suspect they are having a low blood sugar with drowsiness, confusion or feeling cold and clammy.

**Step 2 :** Give the child their ER drink until their parents arrive. It is better to encourage small, frequent sips rather than large amounts in one go. It is also fine for the child to eat if they want to (and are not being sick (vomiting)). If, so please encourage starchy foods like bread, cereal or biscuits.

#### If the child is does not take their ER drink:

If the child is unable to take their ER drink, the child's parents will need to take them to hospital to be given glucose via an intravenous drip as soon as possible.

If the child is being sick a lot (2+ times) or drowsy, please continue to offer sips of their ER drink, if possible, and call an ambulance. Please show the paramedics this leaflet and any alert card you have been given.

## Frequently asked questions

#### Does blood sugar monitoring need to be done at school/nursery?

Most children will not need blood sugar monitoring whilst at school/nursery. If the child's consultant feels it is necessary, the Children's Metabolic Specialist Nurse will facilitate training/education for staff as appropriate.

## Is there a special diet required for children with ketotic hypoglycaemia?

No. Children with ketotic hypoglycaemia should have a normal varied diet like any other child, but should have some starch with each meal (for example, pasta/bread.potatoes/rice). It is important that someone checks what they eat. If the child has eaten part of their meal and is well, there is no need to worry. Please tell parents when they collect their child so they can ensure the child has enough to eat at home.

#### Do children with ketotic hypoglycaemia need any snacks between meals?

Snacks are not needed between meals. However, the child should be given a starchy snack, for example, a cereal bar or some biscuits, if the child is taking part in prolonged sport. Parents will have been advised of a suitable product and should leave a supply at school for use as needed.

#### Are there any special considerations in terms of activities at school/nursery?

Children with ketotic hypoglycaemia can be involved and take part in all normal activities, including P.E. If the child is going on a school trip it is very important that the child's ER drink and management plan for illness is taken with them should they become unwell.

#### **Contact details**

Please contact the Metabolic Specialist Nurse if you have an questions :

Tel: 07921545407

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