

Ketotic hypoglycaemia (KH)

This leaflet gives more information about KH. If you have any questions or concerns, please speak to the metabolic team.

What is KH and why does my child have it?

Ketotic means high level of ketones in the blood. Hypoglycaemia means low blood glucose levels. KH is a common symptom of fasting hypoglycaemia in children. It usually presents in children aged from 6 months-5 years of age. Children tend to outgrow this after 6 years of age, but this can vary.

Usually the body uses glucose for energy from the foods that we eat. Once we have used this our bodies use stored glucose in the liver (glycogen) and then our stored fats. Our stored fats cannot be used directly by the brain for energy and so they need to be converted into ketones before they can be used. Ketones are mainly made and used by the body during times of illness or prolonged fasting, or when not eating or drinking as much as usual.

When children with KH are unwell, for instance, with diarrhoea and vomiting (being sick), they are at increased risk of having hypoglycaemic episodes. Children with KH will make ketones normally, but they can build up and make children unwell when produced in excess when they are ill.

How KH is treated

Children must maintain a healthy, balanced diet, the same as any other child, when they are well. It is only during times of illness or prolonged fasting that the emergency regime (ER) is needed. This may also be known as SOS and will be given at first by the metabolic dietitian and then by your child's GP.

The ER is a specific-to-age concentrated glucose drink, that gives the body enough energy. This will make sure that the body has enough glucose and so is not relying on converting and using ketones for energy.

What happens if your child is ill?

When unwell with symptoms such as diarrhoea or vomiting, or with illnesses that cause reduced feeding, children with KH are at risk of becoming hypoglycaemic as they do not use their ketones efficiently.

The ER should be given as directed. It needs to be mixed with water and given every 2 hours. In the event of diarrhoea, the recipe that includes Dioralyte™ should be used. If the ER is not tolerated (refused or vomited) you will need to go to your local hospital for intravenous (through a vein) dextrose (a form of sugar) until your child is feeding normally again. If you are at all concerned then administer the ER and go to your local hospital for review.

If you need advice when starting ER at home, or illness continues for longer than 24 hours, contact us for advice.

Please make sure that you tell your child's nursery, school or child minder about KH and give them the ER to use when needed.

Contact us

If you have any questions or concerns about your child, please contact the metabolic team, **t:** 020 7188 7188

Clinical nurse specialist, **t:** 020 7188 0855, Monday to Friday, 9am-5pm. Out of hours, please call the hospital switchboard, **t:** 020 7188 7188, and ask for the bleep desk. Ask to bleep the specialist registrar covering paediatric metabolic and wait for a response. This will connect you directly to them.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.evelinalondon.nhs.uk/leaflets

Evelina London Medicines Helpline

If you have any questions or concerns about your child's medicines, please speak to the staff caring for them or contact our helpline.

t: 020 7188 3003, Monday to Friday, 10am to 5pm **e:** letstalkmedicines@gstt.nhs.uk

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk
t: 020 7188 3514 (complaints) **e:** complaints2@gstt.nhs.uk

Language and Accessible Support Services

If you need an interpreter or information about your care in a different language or format, please get in touch.

t: 020 7188 8815 **e:** languagesupport@gstt.nhs.uk

NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

t: 111

NHS website

Online information and guidance on all aspects of health and healthcare, to help you take control of your health and wellbeing.

w: www.nhs.uk

Leaflet number: 5085/VER1

Date published: October 2020

Review date: October 2023

© 2020 Guy's and St Thomas' NHS Foundation Trust

A list of sources is available on request