

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 your child has 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 6 months to 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. When 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 have an increased risk of having hypoglycaemic episodes. Children with KH will make ketones normally, but they can store up and make the child unwell when there are too many when they are ill.

Treating KH

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 concentrated (strong) glucose (sugar) drink that gives the body enough energy. The strength of the amount given will depend on their age. This will make sure that the body has enough glucose, and so is not relying on converting ketones for energy.

What happens if your child is ill?

If your child has KH and is unwell with symptoms such as diarrhoea or vomiting, or with illnesses that cause reduced feeding, they 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 (IV, through a vein) dextrose (a form of sugar) until your child is feeding normally again. If you are concerned, administer the ER and take your child 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, **phone:** 020 7188 7188

Or the clinical nurse specialist (CNS), **phone:** 020 7188 0855, Monday to Friday, 9am to 5pm. Out of hours, please call the hospital switchboard, **phone:** 020 7188 7188, and ask for the bleep desk. Ask to bleep the specialist registrar for children's metabolic conditions, and wait for a response. This will connect you directly to them.

For more information on conditions, procedures, treatments and services offered at our hospitals, please visit **website:** 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, **phone:** 020 7188 3003, Monday to Friday, 10am to 5pm
email: letstalkmedicines@gstt.nhs.uk

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS), **phone:** 020 7188 8801 **email:** pals@gstt.nhs.uk. To make a complaint contact the resolution department **phone:** 020 7188 3514 **email:** 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 contact the department your appointment is with.

NHS 111

This service offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day, **phone:** 111
web: www.111.nhs.uk

NHS website

This website gives information and guidance on all aspects of health and healthcare, to help you take control of your health and wellbeing, **web:** www.nhs.uk

Get involved and have your say: become a member of the Trust

Members of Guy's and St Thomas' NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, please get in touch, **phone:** 0800 731 0319 **email:** members@gstt.nhs.uk
web: www.guysandstthomas.nhs.uk/membership

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