

Managing MCADD in children - a genetic metabolic disorder

Children's Metabolic Service

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This booklet gives information and advice for schools and childcare settings about MCADD. Children with MCADD are seen by the Children's Metabolic Team at the Leicester Royal Infirmary.

Please contact the Metabolic Specialist Nurse on **0116 204 7854** if you have any questions.

What is MCADD?

MCADD stands for medium-chain acyl-CoA dehydrogenase deficiency.

MCADD is an inherited metabolic disorder. Metabolism is the process where you get or make energy from the foods you eat. A metabolic disorder happens when abnormal chemical reactions in your body disrupt this.

MCADD means a person has problems breaking down fat to use as an energy source. Symptoms may include being sick, drowsy, developing liver failure and low blood sugar levels.

All babies born in the UK are screened for MCADD as part of the new-born screening test (also known as the heel prick test). MCADD is a rare condition, around 1 in every 10,000 babies are born in the UK with MCADD.

People with MCADD lead normal, healthy, and active lives. It should not cause the child any problems when they are well and eating normally. MCADD only becomes a problem during illness or fasting. When unwell, children with MCADD have difficulty breaking down fats in their body quickly enough to give them the energy they need. They can become unwell very quickly and may need to be seen in hospital.

**Health information and support is available at www.nhs.uk
or call 111 for non-emergency medical advice**

Visit www.uhleicester.nhs.uk for maps and information about visiting Leicester's Hospitals
To give feedback about this information sheet, contact uhl-tr.informationforpatientsmailbox@nhs.net

How is MCADD managed?

Children with MCADD must eat regular meals through the day containing starchy carbohydrates. Each child will have a safe overnight fasting time which increase with age. From the age of 1 years children can safely fast overnight for up to 12 hours, this is if the child has eaten normally throughout the day.

As long as children with MCADD are eating normally they will not have to break down the fats in their body and MCADD should not cause the child any problem.

If a child with MCADD fasts for too long or becomes unwell, for example, with a high temperature or vomiting, it is very important to act quickly.

To prevent the child becoming so unwell it is important for children with MCADD to start their oral **emergency regime (ER)**.

Oral emergency regime (ER)

The emergency regime (ER) involves them drinking a high sugar drink. This ER drink gives the child's body with the energy it needs quickly. You need to give this quickly because children with MCADD cannot clear the toxins that build up in the blood. A build of these toxins is sometimes called a metabolic crisis. This is why it is really important to start treatment without delay to prevent this.

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

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

How much ER to give your child:

Age	Emergency Regimen Drink (1 Sachet made up to 200mls of water)
0 to 1 years old	SOS 10
1 to 2 years old	SOS 15
2 to 10 years old	SOS 20
10 years old or older	SOS 25

If the child becomes ill at school/childcare setting:

Step 1: Contact parents right away if the child is unwell or you suspect they are unwell. For example, being sick (vomiting), high temperature, tiredness (lethargy).

Step 2: Give the child their ER drink while you wait for their parents to arrive. It is better to encourage small, frequent sips rather than large volumes in one go. It is also ok for the child to eat if they want to (as long as they are not being sick (vomiting)). Please encourage starchy foods like bread, cereal or biscuits.

What to do if the child does not take their ER?

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 through a drip as soon as possible.

If the child is being sick a lot (more than 2 times) or drowsy, please continue to offer sips of their ER drink and call an ambulance saying that the child has a metabolic disorder called MCADD.

Frequently Asked Questions

Is there a special diet needed for children with MCADD?

No. Children with MCADD should have a normal, varied and healthy diet. It is important that someone checks the child has eaten their meals at nursery/school. If the child has eaten part of their meal and is well there is no need to worry. Please tell parents/carers when they collect their child so they can make sure their child has enough to eat at home.

Does a child with MCADD need any snacks between meals?

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

Any special considerations in terms of activities at school/nursery?

If the child is going on a school trip it is very important the child's ER drink and management plan for illness is taken with them in case they become unwell.

