

## MCADD: Dietary information for parents/families

This information sheet will provide you with a very brief introduction to the dietary treatment of MCADD. Much more detailed information, including written guidelines will be given to you by your Dietitian.

*If you do not talk to a dietitian for information on normal feeding and the illness plan at your initial hospital appointment please inform your Doctor.*

### Follow-up of the MCADD screening result at hospital

- If your baby has a positive screening test for MCADD, you will be seen in hospital by the MCADD Team within 24 hours.
- At hospital you will meet the Doctor, Dietitian and Clinical Nurse Specialist. They will provide you with all the information you need to manage MCADD. You will continue to see this team at regular intervals as your baby grows-up.
- Your GP and local hospital will also be informed about how to manage MCADD

### What is the problem in MCADD?

- When we fast (go without feeds/food) our body uses its own fat stores for energy. People with MCADD have a problem in producing energy from their body fat stores. During illness the body uses fat as its main supply of energy.
- If a baby/child with MCADD becomes unwell and feeds poorly, or has vomiting or diarrhoea they will become drowsy, irritable or not respond normally. This happens because they are not able to make enough energy from their body fat stores. We can help prevent this by giving 'glucose polymer powder' to supply energy.

### What is the dietary treatment for MCADD in the well baby or child?

- **Babies** with MCADD can be fed normally: either breast feeding or normal infant formula every 3 to 4 hours. However, it is important babies do not fast for longer than 6 hours (day or night). Older babies can fast for a longer time.
- If your baby is prescribed a special infant formula by a doctor or dietitian, check with them that it does not contain added Medium Chain Triglycerides (MCTs) This is a type of fat that your baby cannot readily use to make energy and needs to avoid.
- You can wean your baby onto a normal diet at the usual time around 6 months (26 weeks) of age.
- **Children** with MCADD can eat normally, but need to eat regularly. At night they can fast for 12 hours unless they are unwell or have not been eating well during the day.
- Very few foods contain MCTs and usually the amounts are so small that they do not cause a problem. Your Dietitian will discuss this with you in more detail.

### What is the dietary treatment for MCADD in the unwell baby or child?

- If your baby/child is unwell and/or not feeding well then very frequent feeds/drinks of glucose polymer need to be given. This is called the 'Emergency Regimen'. Glucose polymer will provide energy and help prevent the body fat stores being used for energy.
- The dietitian will give you an easy recipe to make the glucose polymer feeds/drinks and advise how much and how often to give. This will change at age 1 year, 2 years and 10 years.
- If your baby/child is not tolerating the emergency regimen they will need to go to hospital.
- Your GP will prescribe the glucose polymer which you will get from the pharmacy.