

Hospitalised with MCADD

Averting a metabolic crisis by infusion

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This week we experienced the first time that our son was hospitalised since he was diagnosed with MCADD, a metabolic condition that limits his body's ability to utilise fats for energy. Do you or your kid have MCADD? Then, read along and don't worry, as everything will be alright!

Explaining MCADD

Like a marvellous machine, your body can utilise many different resources to power itself. You can practically eat anything and through the magic of the metabolic system, your food is converted into energy.

When you run out of food, your metabolic system eventually turns to burning body fats. The so-called MCAD-enzyme prepares the fatty acids for energy conversion. Patients diagnosed with MCAD-deficiency, or MCADD, have trouble producing (enough) MCAD-enzymes to make this work.

Without enough MCAD-enzymes, the body runs into metabolic crisis after it depletes its supply of [glucose](#) and [glycogen](#). Unprocessed fatty acids can become toxic if your body is unable to get rid of them. Running out of energy and toxic blood levels will ultimately kill you.

The Danger of MCADD

Under normal circumstances MCADD is relatively easy to manage, just make sure you eat or drink (something) regularly. It doesn't have to be much, as long as it keeps your body from running out of energy. MCADD becomes a problem when the food intake is disrupted, like in case of a regular illness causing you to vomit. An empty stomach in combination with fever is especially dangerous as your body will then require even more energy.

Vomit

Out of the blue our son started vomiting! Apparently, he did not feel well and threw everything out. This caused our immediate concern as our son is diagnosed with MCADD. We are well aware of the procedures and tried to offer him some food and sugary drinks after we cleaned the mess.



Ella's Kitchen fruit pouches are a perfect way to offer something sugary - we always have a few in stock for MCADD emergencies

Unfortunately the fruit pouches didn't work as they almost directly came out again! Following the standard procedures, I contacted our doctor at the hospital. Because of the MCADD diagnosis, the hospital knows our son and his condition. This saves me the explanation in case of emergency. When I called our doctor we agreed to try to administer a special fluid aimed to deliver sugar while limiting the chance of vomiting.



Magic potion from the local academic hospital (UMC Amsterdam)

Living near the hospital (± 15 minute drive) is a great convenience, it allowed me to pick up the specially prepared fluid and get back in time. Relax, as patients with MCADD do not immediately go into metabolic crisis: depending on age and body mass it can take hours before the situation gets really dire. But, considering the risks, you don't want to stretch your luck by pushing the time limits either.

Shortly after administering the fluid our son threw it out again! The magic potion didn't work and the risky situation remained. By this time our son started to appear a bit drowsy - reason for extra concern. I contacted the hospital again and we agreed to pack our bags and head for the emergency room!

Hospitalised

The hospital was already expecting us and shortly after our arrival we were directed to a chamber in the emergency room of the UMC Amsterdam. Following MCADD emergency procedures, our son was hooked onto an infusion system. A simple glucose fluid is then directly fed into the blood stream, bypassing the stomach and digestion system, preventing further vomiting.



Bring your bunny rabbit when you're going for an infuse!



Hello from the emergency room - connected to the infusion system

Almost instantly our son responded to the glucose feed, like with a fresh set of batteries our son started talking and making his usual jokes again! It worked and I felt relieved, knowing that a metabolic crisis was averted!

Emma kinderziekenhuis Amsterdam

With the infusion system working our son was perfectly safe, but it was suspected that it would take some more time before he would eat and drink normally again. A regular cold, or a simple flu can take a few days to overcome. During this time our son stayed in the Emma Kinderziekenhuis. It is a special department of the UMC Amsterdam with spacious rooms to accommodate a child plus parent. Nurses and other staff are extra friendly and attentive to their young patients.



Nurses explain what they measure - making the kids (and parents) feel comfortable in the hospital



The hallways in the Kinderziekenhuis are full of interesting things to allow the kids a little break from being a patient - I'll happily play along!

After a few days of incrementally returning to normal food and drinks, the infusion system was disconnected. Our son felt fine again and learned a lot about how things are done in an academic hospital. Before we left, we thanked everybody for what *almost* felt like a little family holiday! :-)

Conclusion

There is a first time for everything, they say. This was our first emergency MCADD hospitalisation for our son. There was no anxiety, panic or stress: thanks to the amazing professionalism of the hospital staff everything felt very natural and smooth.

I would almost recommend it to anyone, ha! No, seriously: the fantastic care we

received deserves a 5-star review. I can't emphasise enough how grateful I am. THANK YOU, Emma Kinderziekenhuis!