

Managing illness while on a ketogenic diet for those that are fed by mouth and/or tube fed (children)

Nutrition and Dietetics

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Information for parents/carers

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Introduction

The leaflet will guide you on the best way to manage the ketogenic diet when your child is unwell.

It is difficult to know how your child will react to illness. The most important thing is to try to minimise their symptoms. The effect of illness on ketones can vary. The ketones might increase or they might drop. This can happen if your child is struggling to tolerate the fat in their ketogenic diet or if they have been given new medicines to help treat their illness or symptoms.

Your dietitian can adjust the ketogenic diet plans if needed. If you have any concerns or questions contact your dietitian.

Vomiting and diarrhoea

Please contact your local doctor as you would normally if you are concerned about your child's health. Children can quickly become dehydrated when they have vomiting and diarrhoea. Take your child to the Emergency department or call an ambulance if you are concerned. Your child may need to be admitted to hospital to get intravenous fluids (IV). This is when a special liquids are injected into a vein to help treat dehydration.

Check your child's blood ketones and blood sugar every 4 to 6 hours to make sure the ketone levels are not rising too quickly and blood sugar is not low. The leaflet will give you advice on treating high ketones and/or low blood sugar.

Your child is unlikely to tolerate their usual Ketogenic feeds through the nasogastric tube (NGT) or gastrostomy (PEG) if they are vomiting and/or diarrhoea. If they usually eat some solids as part of their ketogenic meal plans they may not tolerate their usual recipes due to the fat content.

**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

Ketogenic meals

It may help to halve the level of fat (butter, double cream, oil or mayonnaise) in the meal.

Your child may tolerate a Keto formula feed as a meal replacement better at half strength.

If your child drinks then offer them these regularly throughout the day:

- water,
- no added sugar squash,
- diet fizzy drinks (such as 7up free or sprite zero),
- soda water.

If your child cannot drink then give regular flushes of cool boiled water through the NGT or PEG tube.

If the illness continues past 24 hours (1 day) and/or their ketones are rising above their normal levels your child may need some Dioralyte. This will replenish their electrolyte (sugar, sodium and potassium) levels. Dioralyte contains carbohydrate so your dietitian will need to give you specific advice for your child's ketogenic diet prescription. Talk about this with your doctor or dietitian.

How do I make NGT or PEG Keto formula feeds?

You can make half strength feeds by adding half the normal ingredients and adding the normal volume of cool boiled water.

Give small feeds every 2 to 3 hours or as often as you can.

Give plenty of fluid flushes to prevent dehydration. Your child should be peeing frequently.

Your child may need Dioralyte to replace the electrolytes that are lost in vomit and diarrhoea.

When do I start giving regular feeds?

Once the symptoms are getting better you can slowly build up the strength of the feeds until you reach the normal recipe.

For example:

1. Half strength feeds for 2 to 3 days. If your recipe contains Liquigen then give only 1 quarter of the dose or half of the usual dose.
2. Increase to full strength feeds for 2 to 3 days. You can give half of a dose or 1 full dose of Liquigen.
3. Then go back to the normal feeding plan.

Your dietitian can help you to decide when to increase the strength of the feeds.

What if my child has a fever (cold or virus)?

Please contact your GP if you have any concerns.

- You may want to give your child extra water flushes through the NG or PEG tube to keep them well hydrated. Contact your dietitian for advice on this.
- You can give your child Paracetamol or Ibuprofen. Please make sure you are giving the correct dose. Please see the manufacturer's guidance or your doctors' prescription for advice on doses.
- Antibiotics or other medications should be sugar free. Crushable tablets or capsules tend to have very little carbohydrate.
- Sugar free preparations like Calpol, Nurofen and pharmacy own brands may be acceptable but will still contain some carbohydrate so the ketones may drop slightly.

What medicines can I give my child?

If your child needs a medication, your dietitian can adjust the diet to account for the medications and maintain ketone levels if needed.

We recommend:

- Calpol Six-plus Fastmelts Oro-dispersible paracetamol tablets 250mg
- or Nurofen Meltlet 200mg Orodispersible Ibuprofen tablets

These medications are available to buy. Please make sure the dose of these are adjusted according to your child's weight. Please refer to your letter from the ketogenic consultant regarding the dose that you should give. Ask a member of the ketogenic diet team for advice if needed.

High ketones (hyperketosis): higher than 5.0mmol/L

Ketones can increase unexpectedly when a child is unwell or a recent change has been made to the diet. Your child's blood ketones may be greater than 5.0mmol/L.

Symptoms of high ketones

- Tiredness (lethargy / fatigue)
- Irritability
- Fast breathing or panting
- Increased heart rate
- Face or cheeks turning red (facial flushing)
- Unexpected vomiting

If you suspect your child is experiencing the above symptoms:

- Check your child's ketone levels.
- Check your child's blood glucose levels.

It rarely happens. If your child has the above symptoms and/or ketones are high, the body needs some carbohydrate to reduce the ketones back to normal range. Call your Ketogenic dietitian if you have any questions or worries about this.

Treatment for high ketones: higher than 5.0 mmol/l

1. If ketones are more than 5.0mmol/l give 1 level scoop of Polycal powder dissolved in 30 to 50ml cool boiled water. Give this through NG or PEG tube.
2. Check the ketone levels in 20 minutes. If they have not decreased to under 5.0mmol/L then treat again.
3. Check ketone levels in 20 minutes again. If they have not decreased to under 5.0mmol/L treat again and get advice from your dietitian, local doctor or go to your nearest Emergency department.
4. Your child may need to come to the hospital. It is very rare that this happens. You will need to continue to check the ketones and treat every 20 minutes as needed on the way to hospital.

If you are in any doubt as to whether you should treat or not, please be safe and treat as above. The consequence will be lower ketones for a time but you and your dietitian can work together to sort this out.

Low ketones (less than 2mmol/l): no action

Sometimes ketones may be lower in the morning after the overnight fast without any fat. If the ketones are under 2mmol/l, this does not need any action. Ideally we would adjust the ketogenic diet recipe to make sure the ketones are consistently above 2mmol/l but this is not always possible. Tell your dietitian if the ketones are regularly lower than 2mmol/l.

Low blood glucose (sugar): less than 2.5mmol/l

Children on ketogenic diets often have lower blood glucose (sugar) levels than those children on a normal non-ketogenic diet. This is not a problem until the blood glucose levels drop below 2.5mmol/l and/or symptoms develop. This is called hypoglycemia. This happens so rarely that we do not routinely check blood sugar levels at home. We only do this when we start the ketogenic diet and if your child is unwell and/or admitted to hospital.

Symptoms of low blood glucose

- Blood glucose less than 2.5mmol/l
- Tiredness (lethargy / fatigue)
- Irritability
- Sweating / becoming cold and clammy
- Dizziness
- Jittery
- Confusion



- Aggressive behaviour
- Pale appearance (pallor)

If you think your child has the above symptoms:

- Check your child's blood glucose levels.
- Check your child's ketone levels.

Treatment for low blood glucose

1. If blood glucose is under 2.5mmol/l treat it with 2 scoops of Polycal powder dissolved in 50ml cool boiled water. Give this through the NGT or PEG tube. This is double the amount of treatment that we use to treat high ketones.
2. Check the blood glucose in 20 minutes. If it has not increased to above 2.5mmol/l then treat again and **call 999** for an ambulance. Your child may need to be admitted to hospital for an IV infusion.
3. While getting help, continue to check the blood glucose levels every 20 minutes and treat as above until the reading increases to above 2.5 mmol/l.

If you are in any doubt as to whether you should treat or not, please be safe and treat as above.

If the blood glucose is 2.5mmol/l or above and the ketones are under 5mmol/L there is likely another reason for your child's symptoms and he/she does not need treatment with extra carbohydrate.

Contact details:

Specialist Ketogenic Paediatric Dietitians

Leicester Royal Infirmary

0116 258 5400

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔
على هذه المعلومات بلغة أخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل

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