

After Starting The Ketogenic Diet



What will I need to monitor?

Use and fill out the diary! Check urine ketones morning and evening!

Record the number of each seizure type each day.

If your child has very frequent seizures a rough estimate is enough.

Record any changes in mood, alertness, behaviour or general health weekly.

What will be monitored by the paediatric team?

The paediatrician and dietitian will see you and your child regularly in outpatients.

Your child will have blood and urine tests.

The paediatric team will monitor your child's growth (height and weight), health, the epilepsy and the need for change in medication.

What if my child loses ketosis?

If possible, check that your child has not been cheating.

Make sure that the portions have been calculated and weighed correctly.

Sometimes ketones are lost when a child develops an infection.

Don't worry; stay on the diet, ketones will reappear.

What if my child cheats on the diet?

Don't worry, mistakes happen.

Restart the diet with the next meal.

Your child may lose ketosis briefly and have more seizures.

This will settle once the diet has been re-established.

Can my child have other medication?

Yes, but the sugar and calorie content needs to be checked.

Low calorie, carbohydrate-free medicines are best, however sugar-free does not necessarily mean carbohydrate-free. If in doubt ask your pharmacist or paediatrician.

The carbohydrate in the medicine may need to be included in your child's diet by your dietitian.

Let your dietitian and paediatrician know all the medicines your child is taking including homeopathic medicines, complementary medicines and vitamin supplements.

What shall we tell the nursery, school, respite care and other carers?

They need to be aware of your child's special diet.

Please give the "I am on the ketogenic diet" information sheet to people looking after your child.

No other food is allowed.

Can my child have school lunches or meals in respite care?

Yes, but only if your child's diet is strictly followed.

You could provide the carers with a packed lunch or frozen meal.

Can we go on holiday?

Yes. Self-catering holidays are best unless a hotel will stock your prepared frozen meals in a fridge.

Please discuss this with the hotel before you go.

Can I calculate the diet myself?

No! A skilled and experienced paediatric dietitian must calculate the diet so that the diet is safe and nutritionally adequate.

Can I exchange recipes?

No. Recipes cannot be exchanged as the diet is calculated individually for your child alone.

How will we be able to manage birthdays and holidays?

Most of us are used to celebrating special occasions with friends and family, having fun and yes, food.

These days can still be special, but they need not be food centred.

Your dietitian may have other suggestions, if food is important.

What if my child refuses to eat?

Don't panic! The diet is based on changes seen in fasting, so missing a meal is all right.

If your child is unwell contact your doctor.

What must I do if my child is unwell?

If you are concerned about your child's health at anytime contact your local doctor.

Always ensure that they know your child is on a special diet.

They may want to contact your paediatric team.

Please see detailed advice sheet for information on how to manage illness on your ketogenic diet.