

Parent Information Sheet The Ketogenic Diet



What is the ketogenic diet?

This is a high fat, low carbohydrate and low protein diet used in the treatment of epilepsy.

How does the ketogenic diet work?

When fasting or starving your body produces chemicals called ketones, which provide energy.

A high fat and low carbohydrate diet will also cause your body to produce ketones. These ketones seem to have an anti-epileptic effect in some people.

However the exact mechanism is not yet known and there may be more than one way that the diet works.

What type of seizures is the ketogenic diet effective for?

It can be effective for children with any type of epilepsy.

How soon will we know if the diet is working?

Some children improve within a week while others show a slower response and take up to 3 months to respond.

After this time, if sufficient levels of ketones are being maintained and there have been no beneficial changes, the diet should be stopped.

How will my child feel on this diet?

Children respond differently.

Most feel well but in the beginning your child may feel sleepy and miserable.

This improves with time.

Some children become more alert and active.

Will my child feel hungry?

Although the meals look small, they have enough calories and your child should not feel hungry, as fatty food stays in the stomach for longer.

The dietitian will calculate the energy prescription carefully to ensure it is adequate for your child.

How long will my child have to be in the hospital?

This will depend on the unit where your child is treated and on your child's condition.

Sometimes the diet can be started as an outpatient; sometimes your child may need to be admitted.

Can I calculate the diet myself?

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

Recipes cannot be exchanged as the diet is calculated individually for your child alone.

Can my child have sweets or extra snacks?

No! The diet is individually calculated, and divided into the right number of meals to suit your child.

Snack meals can be calculated into the diet, however these must also contain the correct

balance of fat, protein and carbohydrate, or they will reverse the effect of the diet. Sweets are high in sugar, and are not allowed on the diet.

What if my child "cheats" on the diet?

If this occurs ketones will be lost and seizures may recur.

Will medications (anti-epileptic drugs) be stopped after my child goes on the diet?

This depends on the individual circumstances.

In most cases anti-epileptic medications can be reduced or even withdrawn.

This may take some time. (Do not change the dose of medication without asking your paediatric team!)

If the diet seems to be working, how long will my child be on it?

This depends on how much benefit there is from the diet and how difficult it is for you and your child to keep to it.

If your child is seizure-free for 2 years, most doctors would suggest a trial of going slowly back to a more normal diet.

What about the side effects of the ketogenic diet?

In general the diet has very few side effects.

Some children may feel sick or vomit when starting on the diet.

Constipation can be a problem and may need treatment.

Kidney stones have been reported on the diet if children do not drink enough, but are rare.

Sometimes growth can be a problem but most children on the diet will grow normally.

All children are carefully monitored for side effects by the paediatric team.

Will my child become fat?

This can sometimes be a problem if too much food is given or your child is very inactive or physically disabled.

Generally this doesn't happen.

Your child's weight will be carefully monitored.

Is the diet bad for your heart?

The diet is high in fat but this fat is changed to ketones.

These are used by the brain for energy, therefore should not increase the risk of heart disease.

Cholesterol levels are monitored on the diet.

Does the diet require vitamin and mineral supplements?

Yes, these will be prescribed and levels will be monitored with blood tests.

How is the diet monitored?

You will be given a diary to complete and your child will have regular follow-up with the dietitian and paediatrician.

Remind me what are the benefits from the diet?

Although only some children become seizure free, many show significant improvement.

Many children are happier and more alert and make better developmental progress on the diet.

How difficult is the diet to manage?

The diet is often regarded as difficult.

However with care and a basic understanding and specialist advice, it becomes routine.

The dietitian will support and help the family