

THE KETOGENIC DIET INFORMATION SHEET

What is the Ketogenic diet?

The ketogenic diet is a high fat, low protein and low carbohydrate diet used as a treatment for epilepsy. The ketogenic diet may be ordered by the doctor for children who have severe forms of epilepsy that have not responded well to various drug treatments.

The diet is very high in fat, in the form of fatty foods such as butter, margarine, oil and cream. The diet contains enough protein for your child to grow and develop normally and very small amounts of carbohydrate foods.

How does the diet work?

No one is certain exactly how the diet works. Normally, your body breaks down the carbohydrates in the food you eat to glucose, the fuel for the brain. When you do not have enough carbohydrate (such as during starvation) your body starts to break down your fat reserves. When fat is broken down it produces a by-product called ketones. Your brain then starts to burn ketones for energy.

The ketogenic diet provides your child with enough energy to grow, but mimics the effects of starvation. The high fat content makes the body produce ketones in larger than normal quantities, and these are used by the brain for energy instead of glucose. It is the change in fuel for the brain that is thought to make the diet work. Not all children respond to the diet, but those that do may have fewer seizures of decreased intensity, and may even remain free from seizures for extended periods.

Who should go on the diet?

The ketogenic diet is used for children with severe epilepsy where other therapies have failed. Even though the diet involves food, it requires a great deal of effort, is restrictive and will change your child's usual eating habits. Remember that food is not just about nutrition, we eat for social and cultural reasons as well as for pleasure, and all of these factors will be affected on the diet.

A referral will need to be made from your neurologist to a trained Paediatric Dietitian.
The diet must be conducted under medical supervision.

How effective is the diet at controlling or eliminating seizures?

Studies show that approx 1/3 of children treated with the ketogenic diet have greater than 90% seizure control with half of these becoming seizure free. An additional 1/3 gain a 50% reduction in seizures. The remaining 1/3 discontinue the diet due to its ineffectiveness or its difficulty.

What does the diet involve?

An appointment will usually be scheduled as an outpatient to meet the dietitian, to explain the diet and discuss your child's usual eating habits. The dietitian will assess your child's nutritional requirements based on their age, activity level and growth and use this to calculate the diet. On the ketogenic diet, most of your child's energy will come from fat with small amounts of protein and carbohydrate. Your child will be restricted to four meals a day only and the amount and type of food offered is tightly controlled.

The diet prescription for the ketogenic diet is typically in a 4:1 ratio although for some children a different ratio may be required. You will be given the diet prescription that will detail the amount of fat, protein and carbohydrate per meal. The dietitian will teach you how to use a special computer program to assist with calculating menus.

Some factors to take into account are:

- You will need to weigh out all foods
- It is important that all the food at a meal is eaten. Food uneaten at one meal should not be added to a subsequent meal as the portions at each meal are calculated so that fat, protein and carbohydrate are in the correct proportions
- Your child cannot have snacks in-between meals unless this is first negotiated with the dietitian.
- Extra planning and organisation is needed when eating outside the home, e.g., at school, restaurants, friends' houses
- While the child is on the diet, sugary foods must be avoided, as these will rapidly reduce ketone levels. The only circumstances when these items may be used are when blood sugar level falls too low or when ketone levels become extremely high and cause nausea

Starting the Diet

As the diet requires close medical supervision, your child will need to be admitted to hospital for approximately 5 days to commence the diet. The diet usually commences with a fast from dinner (approx 6-7pm) the night before the admission which causes the ketones to build up.

The diet is usually started in reduced quantities and gradually increased over the first few days in hospital. Prior to the admission the dietitian will teach you how to weigh foods and plan and prepare meals at home.

Medications will be checked to make sure that they do not contain sugar or carbohydrate. Your child's blood glucose levels and urinary ketone's will be monitored (see below) throughout their admission.

How long will it take for the diet to work?

The diet may become effective immediately or can take several months. Each child is unique and has different seizure patterns and frequency. If the diet is likely to work there is usually an improvement within the first 10 weeks after commencing the diet.

What is the 4:1 diet?

"4:1" means 4 grams of fat for every 1 gram of protein and carbohydrate combined or
"3:1" means 3 grams of fat for every 1 gram of protein and carbohydrate combined.

Examples of foods that are part of your child's diet are:

- Fats e.g., margarine, butter, cream, oil, sour cream
- Proteins e.g., lean meat, chicken, fish, eggs, cheese
- Carbohydrates eg fruit, vegetables

Your child will be eating large amounts of fats, but limited amounts of proteins and carbohydrates (much less than their normal intake).

What foods do I need to avoid?

The following foods contain large amounts of sugar and thus should be completely avoided:

- Biscuits, iced, chocolate coated and creams
- Cakes, sweet breads and buns, glace fruit
- Chewing gum, including sugarless
- Chocolate, diet chocolate, lollies
- Condensed milk
- Cordials and soft drinks containing sugar, fruit juice
- Sweetened cough syrups, sweetened medications
- Ice creams and ice blocks
- Jam, diabetic jam
- Milk flavourings, Milo, Ovaltine, Quik
- Pies, pastries, puddings
- Sauces, pickles, chutneys
- Sweetened syrups and toppings
- Flavoured yoghurt

Other Names for Sugar:

- Sugar – brown, white, icing, castor etc
- Sorbitol (420), Mannitol (421), Sweetaddin
- Glucose, glucodin, fructose, lactose, sucrose
- Golden syrup, maple syrup, treacle, molasses, corn syrup, honey
- Dextrose, maltose, maltodextrins

Are there any foods that can be eaten freely?

There are some foods called 'free foods' that are low in carbohydrate and protein that are still restricted, but are not included in the meal portions. They are good meal fillers.

- Soda water, mineral water
- Low joule soft drinks with cyclamate/saccharine as sweetener and caffeine free, limited to 200mL per day
- Low joule cordials limited to 200mL per day.
- Low joule jelly eg Aeroplane Jelly-Lite, Cottee's Diet Jelly Crystals.
- Sugar-free lollies (check ingredients) eg Ricci, Double D
- Spices, herbs, salt, pepper, mustard, vinegar, garlic.
- Lemon, lime, essences in small amounts (vanilla, almond, peppermint)

- Artificial Sweeteners: Cyclamate (952) and saccharin (954) (brands include Sucaryl, Sugarella, Hermesetas, Sugarine, Sweetex), Isomalt (953), Acesulphame K (950), Sucralose (Splenda), Aspartame (951).

Hypoglycemia

During the fasting stage, and when the diet is increasing to full strength portions there is a risk your child's blood glucose levels (BGL) will drop (hypoglycemia). Signs include shakiness, dizziness, pallor, sweating or headaches. Your child's BGL will be monitored every four hours during this time and if the levels drop too low, it will be treated with carbohydrate.

How do you check for ketones?

Your child's ketone levels will be checked with a urine dipstick. A blood test can also be performed to check the level of beta-hydroxy butyrate (a ketone). The keto nurse will teach you how to do this.

The fruit and starchy foods will have the most significant effect on the ketone levels in the same way as sweet foods. If the ketone level drops to trace or disappears, omitting the fruit and/or starchy food at the next meal(s) allow the ketones to build up again.

What if my child becomes sick?

Ketones can be lost during illness and infections. If your child does not want to eat then the full diet can be stopped temporarily and replaced with low calorie fluids. The starvation should maintain the ketones. As foods are reintroduced the quantities should be gradually introduced back to full strength so the correct proportions of fat, carbohydrate and protein are maintained.

If you are concerned about your child, contact your doctor. Any medications will need to be sugar-free and if your child receives IV fluids they need to be free from dextrose (glucose).

What about special occasions?

Children should be encouraged to participate in social eating whenever possible. They may need to be supplied with a lunch box of their own food.

Treats of sweets and too much starch or low starch will cause loss of ketones. A small amount of "protein" or "fat" foods can be given as an extra. These would be preferable to give rather than chips, biscuits etc. Ice blocks can be made using low joule cordial or soft drink, trifle or birthday cake can be made with a sugar free sponge, low joule jelly, cream and fruit (from allowance).

Won't my child be hungry?

You may be surprised at how small the amounts of food seem, compared to what your child usually eats. However, the high amounts of fat will satisfy your child's appetite. The circulating ketones can also make your child feel unwell and decrease their appetite. The meals are calculated by the dietitian to provide your child with enough energy to grow and even though the amounts may seem small, remember fat is providing most of the energy and is a very concentrated source of calories.

Are there any side effects?

There are some possible side effects of the diet, including constipation, raised cholesterol levels, renal stones, poor growth, reductions in bone density, altered immune function and altered liver function. These will be monitored before your child commences on the diet and during the diet. It is important that even though we are

treating your child with food, and it may seem safe, it needs close supervision by a neurologist and dietitian. Adequate daily fluid intake is essential to prevent many of the side effects and your child should be encouraged to drink plenty of water.

What about vitamins and minerals?

The ketogenic diet is a restrictive diet, and is not nutritionally complete. Your child will need a multivitamin and mineral supplement and a calcium supplement. The dietitian will assess your child's diet to ensure that no other nutritional supplements are required. Your child's nutritional status will be monitored during treatment.

How hard can a diet be?

Embarking on the ketogenic diet is not easy. It requires motivation, organisation and commitment. Preparing meals is difficult and time consuming, and your child may no longer be able to have their favourite foods. You will need to consider your child's access to foods at home as sneaking foods can be a problem, upsetting your child's ketosis. If your child's ketone levels fall, then seizures may result. Eating as a family, at school, in restaurants will all change and mealtimes can become difficult with children refusing to eat or demanding foods they are not allowed. Some families find this aspect of the diet the most difficult to deal with because food becomes a battleground and is no longer enjoyable.

What do I need to bring to hospital?

You will need to have digital scales that measure in 1 gram increments and a calculator. You will also need to bring in your child's pre-prepared ketogenic meals for the length of their hospital stay. It is best to label each meal individually and plan in advance which meals you will give on each day. If your child is fed via a PEG, the feeds will be supplied by the hospital.

Is the diet forever?

If the diet has been successful, in terms of reducing the number and/or severity of fits, or even in improving behaviour and management of the child, the diet is gradually weaned, in successive stages, back to a normal level. Positive improvements gained while on the diet often remain when the diet has finished. The duration of the diet will depend on your child but can range from 2-3 years. A regular diet is then gradually resumed.

Where do I get more information?

- *The Ketogenic Diet A Treatment for Children and others with Epilepsy* (4th ed) Freeman, Kossoff, Freeman, Kelly (2007)
- *Keto Kid - Helping your child succeed on the ketogenic diet.* Deborah Snyder (2007)
- Matthews friends website www.matthewsfriends.org
- Ketopag website www.ketopag.org
- The Charlie Foundation website www.charliefoundation.org

Adapted with kind permission from Nutrition and Dietetics, Sydney Children's Hospital & from the Charlie Foundation & Nutricia North America (The Ketogenic Diet Journey, a parents Guide)