



# Ketogenic Diets

## What is the ketogenic diet?

The ketogenic diet has been devised to help manage difficult to control childhood epilepsy. In the 1920s scientists noticed that starvation resulted in the control of seizures, but such benefits were lost when food was reintroduced.

The ketogenic diet is very high in fat, adequate in protein (to allow for growth) and low in carbohydrate. The carbohydrate in the diet is provided by a very limited amount of vegetables and fruit. The diet is carefully calculated for children *individually* and is dependent on their age and activity level.

This diet is also the treatment of choice for Glucose 1 transporter (Glut 1) deficiency and pyruvate dehydrogenase (PDH) deficiency. The following information focuses on the use of ketogenic diets for epilepsy.

For this diet we use readily available, 'normal' foods where we can. For certain types of this diet some special products are required and these are available on prescription.

## How does the ketogenic diet work?

The diet aims to mimic the effect of fasting. When we fast our bodies use fat instead of carbohydrate as the main

energy source. In the ketogenic diet fat is used as the main energy source; and when combined with a low carbohydrate intake will cause your body to produce ketones.

For epilepsy the changes in the body caused by the high fat and carbohydrate restricted diet may have an anti-epileptic effect in some people.

Although it has been proven that this diet is useful in reducing seizures in difficult epilepsy, the exact mechanism is not yet known, and there may be more than one way that the diet works.

In Glucose 1 transporter (Glut 1) deficiency and pyruvate dehydrogenase (PDH) deficiency ketones provide an alternative energy source to glucose.

## Is the ketogenic diet suitable for all types of seizures?

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

## Is the diet suitable for children of any age?

The ketogenic diet is used in children, young people and adults. We currently offer the diet for children between three months and 16 years old. In younger babies, more detailed monitoring of the diet may be required.



## **How can my child be referred for this treatment?**

Referrals for the diet as a treatment for epilepsy are generally made by a paediatrician or a paediatric neurologist.

If your child has a history of feeding difficulties, swallowing problems or reflux these problems will need to be assessed and treated by your paediatrician before your child is referred for the ketogenic diet.

## **What are the benefits of the diet?**

Although only some children become seizure-free, a larger proportion show a reduction in seizure frequency. If seizures are better controlled on the diet, it may be possible to reduce anti-epileptic medications, and in some cases, stop them altogether. A reduction of seizure frequency, and side effects caused by anti epileptic drugs, may lead to children being more alert and able to make better developmental progress on the diet.

## **What about the side effects of the ketogenic diet?**

Generally there are few side effects of the diet. These will be discussed if your child is referred for this treatment. All children are carefully monitored for any side effects while they are on the diet. Many of the side effects can be managed by making adjustments to the diet.

## **Will my child be able to come off medications?**

If the diet helps your child's seizures it may be possible to reduce antiepileptic medications over time. This will be discussed with your paediatric neurologist at clinic visits.

## **If the diet helps my child's seizures how long will my child need to be on it?**

How long your child stays on the diet is dependent on how much benefit there is from the diet and how difficult it is for you and your child to continue the diet. This is reviewed at each clinic visit. In most cases, there is a three month trial period of the diet. After this, progress is reviewed and a decision is made about continuing the diet. If after three months, there have been no benefits for your child, the diet could be stopped.

Usually the diet is weaned after two years to evaluate the benefits of the diet for your child and whether you need to continue with the diet or not.

For children with Glut 1 or PDH deficiency, the diet may need to be continued for longer than two years.

## **Can I calculate the diet myself?**

A dietitian skilled and experienced with the ketogenic diet will calculate the diet to ensure that the diet is safe and nutritionally adequate.



## **Will my child become fat?**

Although these diets are all high in fat, your child should not gain extra weight as the calories in the diet are carefully calculated and controlled by the dietitian.

## **Is the diet bad for your heart?**

The diet is high in fat but this is used by the body as a source of energy and there is no evidence that it increases the risk of heart disease, especially when not thought of as a long term treatment. Your child's cholesterol levels will be closely monitored while they are on the diet.

## **Will my child feel hungry?**

The dietitian will calculate the energy prescription carefully to ensure it is adequate for your child. Although the meals may look smaller than a normal diet, they have enough calories and your child should not feel hungry.

## **How difficult is the diet to manage?**

The diet may seem difficult at the start and will take some getting used to. The classical and MCT diets are very precise, and you will need to weigh all your child's food on these diets. Your dietitian will support and help your family and give individual advice on planning meals.

## **How will my child feel on this diet?**

Children respond differently. In the beginning your child may feel sleepy and

more lethargic. This improves with time.

If seizures are better controlled on the diet, it may be possible to reduce anti-epileptic medications, and in some cases, stop them altogether. A reduction of seizure frequency and side effects caused by anti-epileptic medications may lead to children being more alert and able to make better developmental progress on the diet.

## **Can my child have sweets or extra snacks?**

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 and chocolate are too high in sugar and so should be avoided on the diet.

## **How soon will we know if the diet is working?**

Each child responds to the diet differently. You may notice an improvement within a week, or it may take several weeks for you to notice any benefit.

## **My child is on a tube feed – can they still have the ketogenic diet?**

Yes. There is a special formula available designed specifically for ketogenic diets.



## **If my child is on a special diet can they still have the ketogenic diet?**

This will need to be assessed on an individual basis. In most cases it will be possible for the dietitian to adapt your child's special diet.

## **Are there support groups where I can find out more about this diet?**

Listed below are some parent support groups and websites that you may find helpful.

**Matthew's Friends (UK)**

[www.matthewsfriends.org](http://www.matthewsfriends.org)

**The Daisy Garland Charity (UK)**

[www.thedaisygarland.org.uk](http://www.thedaisygarland.org.uk)

**The Charlie Foundation (US)**

[www.charliefoundation.org](http://www.charliefoundation.org)

**The Carson Harris Foundation (US)**

[www.carsonharrisfoundation.org](http://www.carsonharrisfoundation.org)

Further information is also available from:

**The National Society for Epilepsy**

[www.epilepsynse.org.uk](http://www.epilepsynse.org.uk)

Tel: 01494 601300

**The National Centre for Young People with Epilepsy**

[www.ncype.org.uk](http://www.ncype.org.uk)

Tel: 01342832243

**Epilepsy Action**

[www.epilepsy.org.uk](http://www.epilepsy.org.uk)

Tel: 01132108800

**USA Epilepsy Website**

[www.epilepsy.com](http://www.epilepsy.com)

The following American book explains about the classical ketogenic diet. You should be able to order it from another branch if your local library does not have it in stock. Alternatively, you may be able to order a copy to buy from your local bookshop or online retailer.

FKossof E et al (2011) Ketogenic diets: treatments for epilepsy and other disorders. 5th edition.

Published by Demos. ISBN 1 936 303 108

### **Notes**

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Compiled by Ketopag London Branch; Great Ormond Street Hospital, Evelina Children's Hospital, St George's Hospital, London in collaboration with the GOSH Child and Family Information Group

Great Ormond Street Hospital for Children NHS Trust  
Great Ormond Street,  
London WC1N 3JH

[www.gosh.nhs.uk](http://www.gosh.nhs.uk)