ketogenic diet

For some children who continue to have seizures despite trying medication, the ketogenic diet may help reduce the number of seizures they have and may have other positive effects. Dietary treatments for epilepsy are specialised, and are supervised by trained medical specialists.

what is the ketogenic diet?
The ketogenic diet is a high fat, low carbohydrate, controlled protein diet that has been used since the 1920s for the treatment of epilepsy.

The diet is a medical treatment, and is usually only considered when at least two suitable medications have been tried and not worked. The ketogenic diet is an established treatment option for children with hard to control epilepsy. Some adults may benefit from dietary treatments, but more data is needed about the impact and results for adults, and adult treatments are currently only available in a few UK clinics.

Dietary treatments for epilepsy must only be followed with the support of an experienced epilepsy specialist and dietitian (food specialist).

how does the diet work?
Usually the body uses glucose (a form of sugar) from carbohydrates (found in foods like sugar, bread or pasta) for its energy source. Chemicals called ketones are made when the body uses fat for energy (this is called ketosis). The body uses ketones instead of glucose for its energy source. Research in 2015 has shown that another chemical, decanoic acid, is also produced as a result of the diet. These chemicals help to reduce seizures for some people.

who is the diet suitable for?
The diet may not work for everyone but is suitable for many different seizure types and epilepsy syndromes, including myoclonic astatic epilepsy, Dravet syndrome, infantile spasms (West syndrome), and those with tuberous sclerosis. It can be adapted to all ethnic diets, as well as for children who are allergic to dairy products (although this can limit the food choice).

The dietitian will calculate the diet and try to include foods your child likes. If your child has feeding problems, or has a condition where a high fat diet would cause problems, the diet may not be suitable.

what age range is the diet suitable for?
Some clinics offer the diet for children from 12 months old. However it can be used for younger babies in some specialist centres that offer more detailed monitoring.

what sort of food is eaten on the diet?
There are different forms of the ketogenic diet. The types of foods eaten and the way each diet is calculated are slightly different, but each diet has shown effectiveness in reducing seizures for some people.

Classical diet
In this diet most of the fat comes from cream, butter, oil and other naturally fatty foods. It includes very little carbohydrate and protein. Each meal needs a strictly measured ratio of fat to carbohydrate and protein.

Medium chain triglyceride (MCT) diet
This diet allows for more carbohydrates and protein, so offers more variety. It includes some fat from naturally fatty foods, as well as some fat from a supplement of MCT oil or emulsion. This can be mixed into food or milk and is only available on prescription. Unlike the classical diet’s strict ratio of fats to carbohydrate and protein, the MCT diet is calculated by the percentage of energy (calories) provided by the different food groups.

similar dietary treatments for epilepsy
The following diets have more flexible approaches, which may suit teenagers or adults. They are still medical treatments, with potential side effects, and need to be approved by the person’s neurologist. A ketogenic dietitian needs to individually set the diet for each person so that it is safe and nutritious.

Modified Atkins diet (MAD)
The Modified Atkins diet (sometimes called ‘modified ketogenic therapy’) uses a high proportion of fats and a strict control of carbohydrates, but is more flexible than the classical or MCT ketogenic diets because fats, protein and calories are not restricted.
Low glycaemic index treatment (LGIT)
This diet focuses on how carbohydrates affect the level of glucose in the blood (the glycaemic index), as well as the amount of carbohydrate eaten. Approximate portion sizes are used rather than food being weighed or measured.

Is this a healthy way to eat?
To make sure the diet is nutritionally balanced, an experienced dietitian works out exactly how much of which foods the child can eat each day. To help with this, parents have individual recipes for their child, are given support on how to plan meals and are guided on which foods should be avoided. As the diet can be quite restrictive, the dietitian will recommend any vitamin and mineral supplements that are needed.

How is my child’s health monitored?
Regular follow-ups with the paediatrician and dietitian will monitor your child’s growth (height and weight), health, their epilepsy and if there is a need for any change to their anti-epileptic drugs (AEDs), such as changing to sugar-free versions. If the diet is followed carefully, children do not usually become overweight. You may be given a diary to record the number and type of seizures your child has while on the diet. As food can affect how we feel or act, you may be asked to note any changes in your child’s mood, alertness and overall behaviour. It usually takes at least three months to see whether the diet is effective. The length of time a child is on the diet may vary, but if a child remains seizure-free, they may slowly come off the diet after two years.

How is the diet monitored?
To check that the diet is producing ketones, ketone levels are checked using a blood test, or a urine analysis stick, which is dipped into a container of your child’s urine. The blood test involves a small pin prick on the finger (similar to monitoring diabetes). You can decide with your child’s doctor which method to use.

Are there any side effects of the diet?
Constipation is common, partly due to fat taking longer to break down than carbohydrates, and also due to a lack of fibre. Both of these problems can be easily treated. Hunger, vomiting and lack of energy are also common at the start of treatment, but side effects may decrease with time and may be avoided with careful monitoring. Many children report an increase in energy and feeling more alert once they are used to the diet.

Does the ketogenic diet work?
A clinical trial at Great Ormond Street Hospital in 2008 showed that the diet significantly reduced the number of seizures in some children whose seizures did not respond well to AEDs. After three months 4 in 10 (40%) children who started the diet had the number of their seizures reduced by over half, and were able to reduce their medication. Although not all children had better seizure control, some had other benefits such as increased alertness, awareness and responsiveness.

Research studies are investigating how the different diets work, and why dietary treatments are effective for some people and not for others.

How can my child start the diet?
You can discuss the option of your child starting the diet with their GP or paediatrician.

Other organisations
Great Ormond Street Hospital (GOSH)
www.gosh.nhs.uk
Enter ‘ketogenic diet’ into the search box.

Matthew’s Friends
01342 836 571
www.matthewsfriends.org
Information and support for families who are using, or considering, the ketogenic diet for their child.

The Daisy Garland
01803 847 999
www.thedaisygarland.org.uk
Help and support for families around the ketogenic diet, and funding for ketogenic dietitians.

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