

The ketogenic diet for children with epilepsy

This leaflet has been given to you to help answer some of the questions you may have about the ketogenic diet as a treatment for epilepsy in children. If you still have questions after you have read this, please speak to one of the doctors, epilepsy specialist nurses or dietitians in the ketogenic diet team.

What is the ketogenic diet (KD)?

The (KD) is a special diet which is sometimes used to treat epilepsy when other treatments and medicines have not been successful. It is also used to treat children with certain metabolic conditions, for example Glucose transporter deficiency (GLUT1) and Pyruvate dehydrogenase deficiency (PDH). Compared with a child's normal diet, the ketogenic diet is very high in fat and low in carbohydrate. Ketones are produced by the body from fat in the diet when there is very little carbohydrate available to make energy. This is called 'ketosis' and usually ketones can be detected in the blood and urine.

The KD is designed and calculated for each child individually by a specialist dietitian. The dietitian takes into account age, activity levels, usual food requirements, food likes and dislikes as well as any medicines the child is taking. Starting and monitoring a child on the KD therefore requires specialist medical and dietetic supervision. Over time, many parents and carers also become experts on their child's diet.

Several different versions of the KD are used around the world. At the moment there is no evidence to suggest that any one version is better than the others. At Evelina London Children's Hospital, we have used the classical ketogenic diet, the Medium Chain Triglyceride (MCT) diet and a modified diet. Our recommendation is given only after detailed discussion with the parents and carers of each individual child.

The classical KD

This diet restricts the amount of carbohydrate and protein allowed. Children cannot eat high carbohydrate foods such as crisps, potatoes, pasta, rice, sweets, sugar and chocolate. Each meal must be carefully prepared and the ingredients weighed accurately.

The proportions of fats and carbohydrates and proteins in the diet are controlled to give a ratio of fat to protein and carbohydrate which varies between 2:1 and 4:1. A 2:1 classical KD means that the child receives twice as much fat as carbohydrate and protein combined, at every meal and snack. A 4:1 KD means that the child receives four times as much fat as carbohydrate and protein combined, at every meal and snack.

The classical diet can be given to children who are tube fed or who have a gastrostomy. A special ketogenic formula feed is available for these children. If a child is tube fed but is also allowed small tastes by mouth, these have to be carefully weighed to be in the same ratio as the tube feed. The ketogenic dietitian will give suitable recipes.

The Medium Chain Triglyceride (MCT) diet

The MCT diet makes use of a ready-made liquid containing MCT oil. A certain quantity must be taken with every snack and meal but it can either be drunk or used in cooking. For school-age children, this version of the KD may be easier than the classical diet as it is slightly less restrictive.

The Evelina modified KD

This diet is based on a modification of the slimming Atkins diet, which uses a system of 'choices' or 'portions' of fats and carbohydrates allowed each day. Ingredients do not have to be weighed so carefully and the diet is less restrictive than either the classical or MCT diet.

How does the KD work?

Early in the twentieth century, before antiepileptic drugs were available, there was no treatment for epilepsy or seizures. Doctors noticed that some people with epilepsy seemed to be better when they went without food, perhaps because of illness. Under normal conditions, the brain uses glucose from carbohydrates, for energy. When the body is starved of food, sugar and carbohydrate reserves are used up. The brain can switch to use body fats as its energy source instead of glucose. The ketogenic diet mimics this state of fasting, without producing starvation. The main energy source for the body is fat from the diet. Carbohydrates are restricted. Ketones are produced and can be detected in blood and urine.

We do not know exactly why or how the diet works for some people, or how it helps to control seizures. Neuro-transmitters are chemicals which pass messages from one nerve cell to the next. It is likely that the change in the source of energy used by the brain affects these neuro-transmitters in some way, directly or indirectly, and this changes the brain's susceptibility to seizures.

What seizures or kinds of epilepsy is it used for?

Most children with epilepsy take antiepileptic medication, and their seizures are completely controlled. 20-30% of children with epilepsy have seizures which cannot be controlled by medicines. They continue to have seizures which may be intrusive and troublesome (this is called drug-resistant epilepsy). The ketogenic diet does not suit all children and requires careful and time-consuming food preparation by parents or carers. It may also have long-term side effects. For these reasons, it is only recommended for children where treatment with antiepileptic drugs has not controlled their epilepsy and they still have frequent seizures (at least every week).

Children with certain kinds of epilepsy (epilepsy syndromes) appear to respond better than others and the ketogenic diet may be recommended before too many medicines have been tried. Myoclonic Astatic Epilepsy (MAE) and some other myoclonic epilepsies of very young children seem to respond well to the KD.

The KD may be considered in all types of epilepsy where the seizures are frequent and severe. For a very small number of children with epilepsy, the KD might make them worse, because of a so far undiagnosed problem with body chemistry or metabolism. Before starting on a KD we recommend a number of blood tests to try and identify any such potential problems in good time. For some of these children a KD would not be recommended.

How will we start the diet? What help will we have?

Most children will start the diet at home. We do not starve children to induce ketosis at the beginning and instead we introduce the diet gradually over a period of a few days. We may suggest that very young children and those with other complex medical problems are admitted to hospital for a few days with a parent at the beginning.

Following a clinic assessment by the team and a number of blood tests, your dietitian may send you some recipes and drinks to try at home. The dietitian will recommend the most suitable type of KD (classical, MCT or Evelina London diet) for your child. You will then be asked to come to clinic again to

- discuss meal plans and preparation
- learn how to test blood or urine for ketones
- you may be shown how to prepare meals/feeds in the kitchen
- discuss the date for starting the diet
- be given contact details of the KD team.

Your child will have to have some blood tests and may also need a kidney ultrasound scan before starting the diet.

Once your child has started the diet, your dietitian will be in regular contact for the first few weeks by telephone or email, and be available if you have questions and/or problems with the diet. You may be asked to come to another clinic appointment in order to discuss any particular problems with the team.

Once established on the KD your child will have three to nine monthly ketogenic diet clinic appointments as necessary. Blood tests will usually be done at each clinic visit to check for potential complications of the diet. Attendance at outpatient clinics is very important. Please let your dietitian know in advance if you cannot come to clinic so that we can arrange another appointment quickly. Families who are unable to attend appointments regularly will not be able to continue dietary treatment and will be discharged back to the care of the local team.

How will I know if the ketogenic diet is working?

Before starting the diet, the ketogenic diet team will have discussed the goals of dietary treatment for your child. These goals will be reviewed during clinic visits. They may include

- improved seizures – either frequency, severity, or recovery time
- improved wellbeing in between seizures
- EEG improvement – less discharges, less seizures, improved background rhythms
- improved learning and thinking skills
- improved motor skills
- improved sleep.

Approximately one third of children starting the KD will discontinue within three months. This may be for a variety of reasons, including:

- The diet does not seem to be effective (goals not achieved).
- The child cannot tolerate the diet and seems less well on it compared with before.
- The child refuses to eat all of the food given.
- Ketosis cannot be achieved and seizures are no better.
- Side effects outweigh the benefits.

What are the side effects of the diet?

We aim to control seizures with as few side-effects as possible. Your dietitian and doctor may need to adjust the diet and/or dose of medicines in order to reduce side effects. Sometimes adjustments are needed every few days at the beginning.

Side-effects fall into several categories:

1. Predictable: at the start of treatment.

These effects are usually mild and temporary:

- Tiredness and lethargy.
- Changes in your child's seizures.
- Sickness and loss of appetite.
- Changes in weight. This is why we ask that children are weighed every two weeks so that your dietitian can monitor any weight changes and modify diet as necessary.
- Constipation, which may need dietary modifications or occasionally treatment with medicines.
- Hypoglycaemia (low blood sugar level), though this is rare in our experience.

Very occasionally the level of sugar in the blood is low between meals or early in the morning, resulting in lethargy, nausea, vomiting and sometimes pallor and sweating. If there is any doubt, the child should be given a drink containing carbohydrate. If the child cannot take a drink or the symptoms do not improve over 20-30 minutes, you may need to call your GP, or your local paediatric team. In some cases you may need to call 999 or take the child to your nearest emergency department (A&E).

The diet should not be stopped just because your child is a little more tired or more irritable than usual, but please seek advice from the KD team or your local paediatrician/family doctor if you have concerns about this.

2. Later, but well recognized side effects are:

- **Kidney stones.** This is especially likely if children are taking topiramate or zonisamide whilst on the KD. Some children will have a kidney ultrasound scan before starting the diet as a precaution. You should consult your doctor if your child has back or groin pain, pain on passing urine or has blood in his/her urine.
- **High blood cholesterol levels.** The long term effects of the KD on the risk of strokes and heart attacks in adult life are not known.
- **Vitamin deficiency.** The diet lacks several important vitamins and minerals and supplements will be recommended by your dietitian.
- **Lack of growth.** Children who have been on the KD for a number of years tend to be a little shorter than we would expect for their age.
- **Fractures and osteoporosis.** We will monitor your child's bone health carefully while he/she is on the diet and may recommend bone density scans.
- **Irregular menstrual periods.**
- **Easy bruising**

3. Interference with other drugs.

Medicines bought over the counter at a chemist shop or supermarket, as well as medicines prescribed by your doctor may contain sugar and/or other carbohydrates. Please be careful to check with the pharmacist and your doctor that medicines are carbohydrate free. Your dietitian will provide you with a list of suitable children's simple medicines for fever and pain etc.

Your ketogenic diet team doctor and the pharmacist will review your child's other medicines and may recommend some changes before starting the diet. In general tablets which can be crushed or capsules dissolved in water are better than liquids and syrups (which contain sugar and carbohydrates). Note, however, not all tablets can be crushed or dissolved in water – please seek advice from your pharmacist if you are unsure.

If your child is admitted to hospital as an emergency because of an accident or illness, any medicines and fluids he/she is given may contain sugars and carbohydrates and may therefore reduce the effectiveness of the diet.

Please remind all healthcare workers that your child is on the KD and give them contact details of the KD team.

Also please remember that many types of toothpaste and sunscreens contain carbohydrate. If achieving good ketosis and seizure control on the diet does not seem possible we may suggest changing brands. Your dietician will provide you with details of KD compatible brands.

Will my child need to have blood tests?

Yes. We recommend that all children starting on the KD have a set of blood tests before the diet begins and that these tests are repeated at regular intervals (6-12 monthly) whilst your child continues on the KD.

Are there any conditions where the KD should be avoided or used with caution?

The KD can be used for the children with the following conditions, but frequent blood tests and monitoring for possible side effects will be recommended

- history of liver disease/pancreatitis
- family or personal history of high cholesterol or blood lipids
- mitochondrial disease
- history of kidney stones.

Anyone who plans to, or becomes, pregnant while on the KD or taking any anti-epileptic drugs, should seek medical advice as soon as possible.

How is the KD prescribed?

The consultant you see in clinic will usually recommend the diet and may give you more written information. He/she will write to your family doctor asking him/her to prescribe any changes of medicine and extra vitamin supplements for your child.

Your dietitian will give you a list of kitchen equipment you will find helpful before you start the KD, and may ask your family doctor to prescribe a ketogenic diet formula feed if necessary.

Do not stop the ketogenic diet suddenly without seeking advice from the KD team.

Useful sources of information

Epilepsy Action	w: www.epilepsy.org.uk	t: 0808 800 5050
National Society for Epilepsy	w: www.epilpesynse.org.uk	t: 01494 601 400
Matthew's Friends	w: www.matthewsfriends.org	t: 07884 054 811
Daisy Garland Trust	w: www.thedaisygarland.org.uk	t: 020 8473 614

Contact us

Further information contact the KD team:

Anne-Marie McKillup, paediatric dietitian

e: anne-marie.mckillup@nhs.net **t:** 0207 188 9610 (answer phone, leave message)

Martin Smith, epilepsy nurse specialist

e: martin.smith@gstt.nhs.uk **t:** 0207 188 4588

Dr Ruth E Williams, consultant paediatric neurologist

e: ruth.williams@gstt.nhs.uk **t:** 0207 188 3998

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit **w:** www.evelinalondon.nhs.uk/leaflets

Evelina London Medicines Helpline

If you have any questions or concerns about your child's medicines, please speak to the staff caring for them or contact our helpline.

t: 020 7188 3003, Monday to Friday, 10am-5pm **e:** letstalkmedicines@gstt.nhs.uk

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk
t: 020 7188 3514 (complaints) **e:** complaints2@gstt.nhs.uk

Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please get in touch. **t:** 020 7188 8815 **e:** languagesupport@gstt.nhs.uk

NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day. **t:** 111

NHS website

Online information and guidance on all aspects of health and healthcare, to help you take control of your health and wellbeing. **w:** www.nhs.uk

Get involved and have your say: become a member of the Trust

Members of Guy's and St Thomas' NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, please get in touch.

t: 0800 731 0319 **e:** members@gstt.nhs.uk **w:** www.guysandstthomas.nhs.uk/membership

Was this leaflet useful?

We want to make sure the information you receive is helpful to you. If you have any comments about this leaflet, we would be happy to hear from you, fill in our simple online form, **w:** www.guysandstthomas.nhs.uk/leaflets, or **e:** patientinformationteam@gstt.nhs.uk

Leaflet number: 2238/VER4

Date published: December 2018

Review date: December 2021

© 2018 Guy's and St Thomas' NHS Foundation Trust

A list of sources is available on request