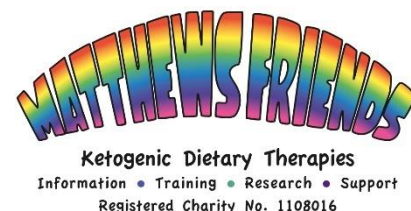


# Ketogenic dietary therapy for adults with epilepsy

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## How effective is it?

Ketogenic Diet Therapy (KDT) first emerged in the 1920's, before most antiseizure medications were discovered, and so the diet was used to treat both adults and children. In fact, the first study to show it as an effective therapy for adults was published in 1930<sup>1</sup> but despite positive results it was almost 70 years before another study reported similar findings. Subsequently, more adult studies have been published using either the classical ketogenic diet or the more liberal modified Atkins diet and summary analyses suggest that effectiveness in adults is similar to that reported in children, with around 40-50% of adults achieving a 50% or greater reduction in seizure frequency and around 13% gaining 90-100% seizure control<sup>2,3,4,5</sup>. Beyond a change in the frequency, intensity and recovery from seizures, adult responders to KDT often report a marked improvement in their mood, alertness, memory, sleep and/or attention span<sup>5,6</sup>.

However, many studies report that adults struggle more in maintaining their ketogenic diet changes longer term. This is the reason why knowledgeable, accessible and adult focused keto-team support is essential in the initial exploratory phase of KDT, when the ketogenic learning curve is at its steepest for all new starters and appropriate diet adjustment is readily required to optimize the outcome.

## Does the treatment differ from children?

The principles of KDT are essentially the same for adults and children, in that the treatment approach must meet the medical, nutritional and lifestyle needs of the individual. Most certainly, the use of more liberal 'modified' ketogenic diets has made this therapy a far more practical possibility for self-caring adults, responsible for delivery and monitoring their own therapy.

For adults reliant on tube feeding (e.g. long-term feeding difficulty or for the acute management of Status Epilepticus<sup>7</sup>), the approach is the same as for children; an individualized feed prescription and close monitoring and adjustment of the feed as required to optimize outcomes. Most ketogenic tube feeds are developed to meet the nutritional needs of children e.g. Ketocal range\* (Nutricia), KetoVie range (Cambrooke) and K.Flo (VitaFlo) but can easily be adjusted to meet the protein and nutrient needs of any adult.

\*Ketocal 2.5:1 is the exception, developed for older children and adults it contains a higher amount of protein. It also contains 25% MCT fat.

International Recommendations for the management of adults treated with KDT were published in 2021<sup>8</sup>.

## Why is medical supervision and support required?

KDT is effectively an antiseizure medication in food form. It needs to be supervised by a neurologist and a dietitian and integrated into the medical treatment plan, alongside existing antiseizure medications. It requires biochemical and neurological screening to ensure that there are no underlying conditions that would make a ketogenic trial hazardous (see 'absolute contraindications' in Table 1). It is also important to check a range of baseline blood measurements before starting and then repeat these at regular intervals throughout KDT to check that the liver and kidneys are working well and that there are no deficiencies in vitamins or minerals.

For most adults, commitment to a three-month trial of supervised KDT is generally all that is required to indicate whether the impact on seizure symptom control and quality of life makes it worth pursuing longer term. When successful, KDT may enable doses of antiseizure medications to be reduced or weaned out altogether and the treatment may continue for two years or longer, depending on personal choice and medical ketogenic team review. If a three-month trial of KDT does not deliver adequate benefits, normal dietary choices (or enteral feeds) are gradually reintroduced.

## Contraindications and cautions for KDT

### Absolute contraindications:

- Inborn errors of fatty acid or carnitine metabolism (generally diagnosed in childhood)
- Porphyrria

### Medical cautions:

A history of:

- Familial hyperlipidaemia
- Renal stones
- Eating disorders
- Inability to maintain adequate nutrition
- Dysphagia (difficulty swallowing)
- Gastro-oesophageal reflux
- Chronic constipation
- Diabetes on medication

### Also:

Pregnancy or planning to become pregnant see

<https://www.matthewsfriends.org/medical-section/ketogenic-dietary-therapies-pregnancy>

### Day to day practicalities of KDT delivery that need to be considered?

Radically changing eating habits can be tough under any circumstances, but KDT is much more than this. It brings with it a new 'responsibility' for delivering the epilepsy treatment correctly, alongside a need for tracking of food intake and symptoms. Even with the best preparation, training and regular support from the keto-team, this can feel very time-consuming, obsessive and quite stressful in the early weeks. However, like learning any new skill, the whole process becomes very much easier in time and if symptoms start to improve, the sense of empowerment can be immense. Successful ketogenic therapy is a team effort with the individual concerned, at the centre of this. The level of involvement, understanding and support of family, close friends and any caregivers, can make a significant difference to the ketogenic therapy experience and outcome.

**The food:** A ketogenic diet requires a considerable change in food choices; cooking meals from scratch (much of the time) and weighing or controlling food portions. Meals generally need to be made from simple raw ingredients so a willingness to cook or regular help from a willing family member or caregiver, is essential. Outside the home, the availability of keto-friendly meals and snacks is limited, therefore forward planning and the packing up of meals and snacks to take to work, college etc. is essential. Moral and practical support from friends, family and even work colleagues can really make a lot of difference.

**The record keeping:** KDT requires careful monitoring and adjustment. This involves keeping accurate records of food intake, seizures, blood ketones (or urine ketones), blood glucose and body weight and sharing this information regularly with the managing keto-team. In this way, the impact of the diet can be tracked, and the prescription adjusted to optimise control of seizure symptoms and manage any side effects if they arise.

**In summary:** KDT is an 'active' therapy choice that may deliver seizure symptom management and quality of life improvements where other medical approaches have failed. However, for various medical, social or lifestyle reasons, it may not be suitable option for all.

### How can you or your loved one gain access to ketogenic diet therapy?

Please speak to your neurologist, epilepsy nurse specialist or your GP in the first instance. They may be able to refer you to a UK adult ketogenic service. Currently these are found via the following link:

Alternatively, they may be able to supervise this locally if they have access to a dietitian with ketogenic experience or are looking to undertake training/supervision to enable them to deliver this treatment locally.

In the meantime, please refer to the Eating for Health & Wellbeing section of this website for simple guidance on more moderate and potentially beneficial changes that can be adopted before considering the ketogenic therapy option.

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