

Ketogenic Dietary Therapies

Prepared and revised by Susan Hill (2016)

This article is about the Ketogenic diet and how it works to treat epilepsy.

The Ketogenic diet is a medical dietary treatment for epilepsy and some metabolic disorders. It is prescribed by a physician, usually a neurologist. A suitably trained registered dietitian is required to be part of the medical team overseeing the therapy. The high fat, adequate protein, low carbohydrate diet can reduce seizures dramatically, and for some, stop them completely.

It is one of the oldest forms of epilepsy treatment available. It's popularity waned from the 1940's onwards with the introduction of newer anti-epileptic medications. There has however been a significant resurgence of interest and use over the past 20 years, mainly for the 30% of patients who fail to respond to drug therapy

How Does It Work?

When carbohydrates in the body are very restricted, our primary fuel (nourishment) source is no longer readily available. As a survival mechanism, stored body fat is used as an alternative source of fuel. If this 'fasting' state continues for a sustained period, residue from using the body fat as fuel produces 'ketones'. The body is then said to be in a state of 'ketosis'. These ketones are thought to have the primary anti-seizure effect, though the exact mechanisms are still being researched. Obviously a prolonged fasting period is not sustainable, so to maintain the state of ketosis, dietary intake is instead manipulated through carbohydrate restriction, with a plentiful supply of calorific fat provided.

How Effective Is It?

Improvement in seizures is seen in up to 60% of a drug resistant population, with some of those patients achieving complete seizure freedom. There are also other degrees of success on the diet such as reduction in medication use and their side effects, increased alertness, and improvement with behavioural problems.

The positive effects of undertaking a Ketogenic diet therapy will often be seen quite soon after commencement, but if this is not the case, the patient will usually be

asked to maintain it for at least 3 months to ascertain whether or not it is going to be effective. If it is, the duration of therapy is usually similar to anti-epileptic medications, where weaning is often attempted after a 2 year period.

Forms Of The Diet

The 'Classical' Ketogenic diet and the 'Modified Ketogenic diet' are the most commonly used forms of the diet in NZ, depending on regional availability and the profile of the patient.

Classical: An individualised and structured meal plan with a (typically) 4:1 or 3:1 ratio of fat to combined carbohydrate and protein. All meals must be carefully prepared, weighed on digital scales, and eaten in their entirety at specific times of the day.

Modified Ketogenic: Also known as the Modified Atkins Diet (MAD), this form uses a set amount of carbohydrates each day with liberal unrestricted amounts of fatty foods and calories, with moderate amounts of protein.

Ketogenic dietary therapies can also be administered as a bottle or tube feed. A number of specifically calculated Ketogenic medical formulas and products are available. In NZ we have 'KetoCal' which can be used as a liquid feed, as a supplement to a solid diet, or in baking.

Availability

DHB funded Ketogenic diet programmes are currently available in some Auckland, Wellington and Christchurch regions. Paediatric patients in other geographical areas are sometimes referred on a case by case basis. There is international consensus amongst published literature that the Ketogenic diet should be offered as a treatment in paediatric complex epilepsy programmes after 2 or 3 failed anti-epileptic medications. However quite considerable medical resources are required with dietary therapies, especially when first initiated, so availability and access remain limited in some regions.

No DHB funded Ketogenic programmes are available for adult epilepsy patients, but some dietitians in private practice offer the service through one to one meetings, Skype, or phone/email consults. Although supervision by a dietitian is still recommended for adults, they generally do not need to be as closely monitored as paediatric patients.

Common Concerns

‘The diet is difficult’ – Spending extra time in the kitchen on Ketogenic meal preparation and diet administration may seem daunting, and the diet does require significant commitment and diligence. However it does get easier with time, and families report that with ‘batch cooking’ and freezing/storing meals, preparation time can be markedly reduced. Families embarking on a Ketogenic diet with their child receive training from their dietitian beforehand, and guidance throughout the duration of the treatment.

‘It is unpalatable’ – All forms of Ketogenic diet are high in fat, moderate in protein and low in carbohydrate. This can be a big adjustment from normal eating patterns. However, wherever possible, the dietitian will ask what the usual meals at home are, and suggest ‘keto friendly’ alternative versions to work within the Ketogenic therapy prescribed. There are also many online Ketogenic recipes and cookbooks available to offer new ideas and choices.

‘Ketogenic diets are not nutritionally complete’ – Additional supplementation of vitamins is essential especially for children. Vitamin and mineral levels are closely monitored, with regular checks carried out to ensure that growth, development and overall health are not compromised.

Support

The medical team overseeing the patient’s Ketogenic therapy regime will provide ongoing support throughout the course of the treatment. Epilepsy New Zealand works closely with Matthew’s Friends NZ who is the NZ support organisation for the Ketogenic diet.

There are also 2 main international support organisations for ketogenic dietary therapies – The Charlie Foundation based in America, and Matthew’s Friends, based in the UK.

NZ has a branch of Matthew’s Friends available to offer local support to families and health professionals. They can be contacted by email and mfnz@matthewsfriends.org , or by phone on 021 998 664.

There is also a closed Facebook group, ‘Matthew’s friends NZ family support’ for families already involved in the Ketogenic diet, or for those wanting to learn more about the therapies.