



AN INTRODUCTION TO KETOGENIC THERAPY FOR ADULTS WITH EPILEPSY



MATTHEW'S
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KETOGENIC DIETARY THERAPIES



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THINKING ABOUT KETOGENIC THERAPY?

The use of ketogenic therapy to manage epilepsy in adults is not new; it evolved back in the 1920's before most of today's anticonvulsant drugs had been discovered.

In 1930 the first clinical trial examining the effect of a Classical ketogenic diet (KD) treatment in 81 adults indicated that half of the adults managed to reduce their seizures by at least a half and one in ten (10%) became seizure free (1). Since then, fewer than 15 small adult trials have been carried out (2-8), with the latest and largest reporting the experience of 139 adults using the more liberal Modified Atkins Diet in 2015 (9).

So, you may be wondering why ketogenic therapy is rarely offered as an option to adults with drug resistant epilepsy even though all other possible treatment options may have been explored and proved ineffective. The main reason for this is the absence of high quality randomised controlled trial evidence in this area. However recent reviews looking at combining the data from a small number of adult trials have suggested that the responder rate is similar to children, with around 40% achieving a 50% or greater reduction in seizures (10).

All ketogenic 'journeys' are individual and there are no guarantees, however many report positive benefits beyond the reduction in seizure numbers such as; improvements in concentration, energy levels and a significant reduction in recovery time when seizures do occur.

Just a three-month monitored trial is generally sufficient to indicate whether ketogenic therapy will deliver significant seizure and symptom change for you, and may be worth continuing longer term.

Contained within this booklet is some information to help you understand the basics of ketogenic therapy; the pros, cons, considerations and practicalities.



SO, WHAT IS A KETOGENIC DIET?

A ketogenic diet is a very low carbohydrate, high fat diet designed to encourage the body to switch its main source of fuel from carbohydrate to fat. Ketones are produced as a by-product of this increased “fat burning” process (this is what is meant by ketosis) and the brain quickly adapts to using ketones as the main fuel source for energy production.

All types of diet are based on regular fresh food ingredients; meats, fish, eggs, nuts, seeds, cheese, vegetable oils, butter, cream, vegetables and fruits.

Classical Ketogenic Diet – where carbohydrate, fat and protein amounts are all measured and carefully distributed to maintain a similar balance (ketogenic ratio) at meals and snacks.

MCT Ketogenic Diet – where carbohydrate, fat and protein amounts are all measured and medium chain triglyceride oil e.g. refined coconut oil is included with each meal/snack. This enhances ketosis and allows more carbohydrates.

Modified Atkins Diet (or Modified Ketogenic Diet in UK) – not so restricted on protein foods but requires measurement of carbohydrate foods and adequate portions of fats at meals.

Low Glycaemic Index Treatment – very similar to a Modified Ketogenic Diet approach in terms of measuring carbohydrate and encouraging fats but restricts the carbohydrate sources to those with a Glycaemic Index of 50 or below.

Ketogenic dietary therapies can be administered as a normal oral diet, via a bottle feed, or tube fed and specific formulas are available.

The crossover between these regimes is significant and often a hybrid may be used, designed around the needs of the individual. Medical screening and monitoring is the same for ALL ketogenic therapies.



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A KETOGENIC DIET IS A VERY LOW CARBOHYDRATE, HIGH FAT DIET DESIGNED TO ENCOURAGE THE BODY TO SWITCH ITS MAIN SOURCE OF FUEL FROM CARBOHYDRATE TO FAT

WHAT'S THE BEST KETOGENIC DIET CHOICE FOR ADULTS?

The **'Modified'** ketogenic diet approach is a good option for those living in an individual home setting, able to initiate and manage changes to food choice themselves and have no difficulties with shopping, cooking or eating.

Those living in a multi-carer home setting or requiring tube feeds as all or part of their nutrition, or have feeding difficulties or a more intermittent appetite may be better with a more structured Classical or MCT ketogenic regime.

WHAT'S A MODIFIED KETOGENIC DIET (MKD)?

This is based on the Modified Atkins Diet (MAD) evolved by Professor Eric Kossoff and ketogenic team at the Johns Hopkins Hospital in Baltimore USA. At the beginning of the treatment phase you will be asked to limit carbohydrate to 20-30g and you will be given guidance on the amounts of fats you need; with diet adjustments being made based on the changes in your symptoms. Further along in the treatment, MCT oil or MCT supplements can be used as a moderator to enhance ketone production IF required.

As with any significant change in diet, it is more difficult to make the switch all in one go. Therefore, we tend to encourage 'step-down' preparation for 4-6 weeks in advance. In this way you have a chance to try out new recipe ideas and become familiar with the basic principles and new food choices etc. This can make the final changeover much easier to cope with.

In summary, Modified Ketogenic Diets can offer more flexibility and can seem easier to manage from a 'food measuring' point of view. However, they still require expert ketogenic team guidance to take you through the various stages, explain the symptom changes and guide you through the process of fine tuning to optimize the effect on seizures and associated symptoms.

HOW DOES A KETOGENIC DIET HELP TO CONTROL SEIZURES?

The brain can use a range of fuels as a source of energy. These include glucose, lactic acid and ketones, with glucose being the fuel used most of the time. A ketogenic diet alters the balance of fuel available to the brain, favouring the use of ketones. It is thought that this brings about a greater stability of brain energy channels and produces many small chemical changes that modify the chain reaction that leads to a seizure occurring. Research is ongoing as there is still much to learn about the many mechanisms of action.



IS KETOGENIC THERAPY FOR ME?

PLEASE CONSIDER THE FOLLOWING ESSENTIAL REQUIREMENTS:

Medical screening by your neurologist or GP:

It is very important to make sure that you do not have any condition that would make a ketogenic trial unsuitable or even hazardous (see contraindications below). It is also important that your blood levels of lipids, various vitamins, minerals and functional markers are checked at baseline before commencing a prescribed ketogenic regime. These are then checked again in 3,6 and 12 months to monitor any change.

CONTRAINDICATIONS:

- Fatty acid oxidation defects, organic acidurias, pyruvate carboxylase deficiency, other disorders requiring a high carbohydrate treatment,
- Familial hyperlipidaemia
- A history of renal stones
- Pregnancy or planning a pregnancy.

CAUTION: The following conditions need to be carefully assessed and appropriately managed prior to diet initiation.

- Dysphagia (swallowing problems)
- Gastro-oesophageal reflux
- Constipation
- Diabetes on medication

A DAY IN THE LIFE OF THE KETO DIET

BREAKFAST TIME

OMELETTE
WITH MUSHROOMS
& TOMATOES
PLUS BERRY SHAKE



MID-MORNING

HANDFUL OF NUTS &
A CREAMY COFFEE



LUNCH TIME

TUNA MAYO WITH
SIDE SALAD AND
CITRUS DRESSING
GOLDEN FLAX BREAD
AND BUTTER



MID-AFTERNOON

TEA & SNACK SIZE
KETO CHOC MUFFIN



DINNER TIME

CHICKEN SPINACH &
MUSHROOM CURRY, WITH
CAULIFLOWER RICE,
BERRIES AND
DOUBLE CREAM



BED TIME

KETO HOT
CHOCOLATE



IS KETOGENIC THERAPY FOR ME? CONTINUED...

A considerable change to your eating habits:

A ketogenic diet generally involves a significant shift in food choices and the way your meals look. To ease you into this, we tend to encourage 'step-down' preparation for 4-6 weeks in advance.

In this way, you have a chance to try out new ideas and become familiar with the basic principles and the types of food you need to focus on. This can make the ketogenic changeover much easier to cope with.

Cooking meals from scratch:

Ketogenic meals generally need to be made from fresh, basic ingredients so a willingness to plan a menu and prepare basic meals is essential. This also means planning meals ahead of time and taking suitable meals and snacks out with you for work, college, travel etc. Eating out becomes easier as you learn more about creating ketogenic meals.

However, we live in a carbohydrate dominant food culture and the availability of keto-friendly meals and snacks is limited, but Matthew's Friends have produced a Handy Guide to Eating Out which may also prove useful for you.

Careful record keeping:

The value of this can't be emphasised enough. You will need to keep daily records of your:

- seizures and associated symptoms
- home blood ketone, blood glucose or urine ketone tests
- diet and any changes made

You will be asked to summarise your monitoring information and email or post this to your managing team each week. During the initial stages of treatment, your diet may need more frequent adjustments to achieve optimum effect and maintaining accurate daily records is essential for this process.

Positive support from friends, family and work colleagues:

A radical changing to your eating habits can be tough under any circumstances but ketogenic therapy is much more than this. You become responsible for delivering your treatment, monitoring the effect and making it work. This can be empowering and worrying in equal measure.

There may be days when you need help with shopping and cooking and so there ideally needs to be at least one other person who understands the principles of your treatment and will work alongside and support you. Moral and practical support from those around you is so important and makes a real difference.



KETOGENIC MEALS GENERALLY NEED TO BE MADE FROM FRESH, BASIC INGREDIENTS SO A WILLINGNESS TO PLAN A MENU AND PREPARE BASIC MEALS IS ESSENTIAL.

A SUMMARY OF THE KEY FOOD CHANGES INVOLVED

Your dietary prescription is designed around your specific nutritional requirements, based on your activity level, your normal diet and any nutrient deficiencies that may have emerged from your baseline screening. Meals and snacks are based on a simple combination of foods that are rich in a wide range of nutrients. You are encouraged to choose as much variety of foods as possible.

Carbohydrate containing foods; a significant reduction

Carbohydrate control is fundamental to the ketogenic fuel switch and a therapeutic ketogenic diet for adults will generally contain 20-30g carbohydrate per day. You will be guided on how much to include at meals and how to spread this through the day.

We recommend choosing carbohydrate containing foods that release their glucose more slowly such as non-starchy vegetables, berries, dairy products, nuts and seeds to provide your prescribed amounts at meals. Weight for weight, these foods are also much lower in carbohydrate than traditional starchy sources, so you can get more food bulk for your carbohydrate allowance. On ketogenic diets, whenever any carbohydrate is eaten, there always needs to be some fat alongside this.

Fats and oils; a significant change from 'normal'

Fats are the main driver for ketone production and become your main fuel; needing to be included in each meal and snack. Examples of good fat sources are olive oil, coconut oil, butter, lard, double cream, mayonnaise, avocados, nuts and cheese. Protein containing foods such as meats, oily fish and eggs in your meals do naturally provide some fats too, but the amounts are not adequate so extra pure fats need to be added at each meal.

Your prescription will provide you with guidance on how much to use and when. Amounts will depend on your body weight, your day to day activity levels and whether there is a need for weight maintenance or weight reduction.

Protein containing foods; 'normal' quantities based on appetite

You will be encouraged to include a normal-sized portion of meat or fish or eggs or nuts or cheese with each meal. On a Modified ketogenic diet, protein foods are not weighed and measured but large portions can deliver much more protein than your body needs, with the excess being burned for fuel. This reduces the need for your body to burn as much fat; impairing ketone production.

Vitamin, mineral and micronutrient supplements

Baseline vitamin, mineral and trace element supplementation is generally recommended alongside ketogenic therapy. This can be provided by a good quality one-a-day A-Z type product aimed at adults. However, very few of these provide calcium, magnesium and Vitamin D in adequate amounts, therefore an additional product may be required.



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A EXAMPLES OF GOOD FAT SOURCES ARE OLIVE OIL, COCONUT OIL, BUTTER, LARD, DOUBLE CREAM, MAYONNAISE, AVOCADOS, NUTS AND CHEESE.

ARE THERE ANY SIDE EFFECTS?

During initiation

As your ketogenic diet is stepped in, your metabolism takes a few days to adjust and this may lead to lethargy, a mild headache or slight nausea. This is quite normal and should clear after a few days.

We advise you to take it easy during the introductory week of your ketogenic diet, to enable rest when you need it and time to think about your new food choices and meal preparation.

Changes to your digestion

A ketogenic diet alters your digestive processes and the availability of food and fuel to the millions of bacteria living in your bowel*. The most common side effect associated with this is constipation. This can readily be managed by ensuring adequate fluids and enhancing fibre intake; choosing large portions of very low carbohydrate vegetables and including ground flax seeds in some of your recipes. Some find that a laxative such as Movicol or equivalent may act as a helpful regulator in the early stages while their system adjusts.

*This may be a very important therapeutic component of ketogenic therapy. Research is underway.

Weight loss or gain?

It is possible to lose, maintain or even gain weight on ketogenic therapy.

Unplanned weight gain is not common but may occur if too much fat and protein is eaten and indicates that your fuel intake is greater than your needs. When your weight is increasing, you will not produce ketones as effectively, leading to lower levels.

Unplanned weight loss will occur if you are not managing to eat all your required fat portions. Once your body is switched into fat burning mode, it will burn the fats you eat or stored body fats if your food fat intake is too low. Therefore, if you are not consuming enough fats, you may lose weight, feel tired and ketone production may be impaired or exaggerated depending on your individual response.

Your prescription will be designed to match your needs and you are asked to weigh yourself weekly (at the same time of day) on digital scales and include this on your weekly monitoring form.



OTHER COMMON QUERIES

What do I do if I am following the Modified Ketogenic diet and I become unwell?

You will be susceptible to the same illnesses as anyone else and will be given guidance on managing routine illness such as diarrhoea, vomiting, colds etc. Ketogenic control is readily affected by illness and seizure symptoms may increase but should return to base level once the illness resolves.

Will I be able to eat out on the Modified Ketogenic diet?

There are more keto-friendly options on pub and restaurant menus these days so the answer is a definite, yes. However, you are likely to need a little time to build up your own meal planning and carbohydrate counting skills before you can step into a restaurant with confidence. The Matthew's Friends Handy Guide to Eating Out (available to download from the website or can be sent to you) can provide you with some helpful tips.

Can I use commercial low carbohydrate food products such as snack bars / cakes etc?

During the initial three-month ketogenic trial phase, it is best to base your meals on simple whole fresh foods.

Some products specifically designed for the Atkins diet contain sugar alcohols such as xylitol and erythritol and sorbitol. Although acceptable for use on the Atkins Diet, they are not recommended to be included in the Modified Ketogenic Diet in the initial stages.

Once you are well tuned-in to any symptom changes the diet has delivered, you may wish to experiment with the occasional low-carb alternative while closely monitoring for any changes in seizure symptom control.



FIRST STEPS TOWARDS KETOGENIC THERAPY

WHERE DO I START?

Before you approach ketogenic therapy, it is worth looking at the 'Eating for improved health and wellbeing being' information (on the following pages) to see if there may be some simple but positive meal adjustments you can try in preparation for this.

In fact, if you find it hard to make the initial changes, it is likely that ketogenic therapy is not right for you at present. However, don't be disheartened, an improvement in your food mix, the timing of your meals and moderating your carbohydrate intake can all have a stabilising effect on your body weight and boost energy levels, helping you to cope better with the challenges of life.

For further guidance and online tutorials about making dietary changes, please refer to Balance by Soul Nutrition website: <http://www.matthewsfriends.org/health-wellbeing/soul-nutrition/>

EATING FOR IMPROVED HEALTH & WELLBEING;

Our choice of food, how much we eat and how often we eat, can have an enormous impact on how we feel from day to day.

Relatively simple adjustments can make a difference, leading to enhanced energy levels, improved weight control and enabling us to feel better equipped to cope with the everyday challenges of life. If you are looking to explore changes, but are not quite sure where to start, then please read on for some tips. Time-wise, it's worth planning moderate and sustainable meal changes over a period of weeks and months. Quick fix diet changes, rarely adjust our comfortable old habits for long.



WHERE DO I START?

Start with where you are right now. Try keeping a diary of what and when you eat for a typical week. It is worth making the effort to do this as it can produce some real surprises. You may find it helpful to take the time to review your diary alongside the following 'checks' and choose one set of changes before going on to the next. Try to focus on the positive; thinking about the types of foods you want to eat more frequently rather than what foods to avoid. By planning changes to your food choices and meal patterns in a series of small steps, you are more likely to achieve longer term improvements that matter to YOU.

CHECK 1 - REGULARITY

Are you eating regularly or do you grab a meal or snack when you can? There's no rocket science here; we tend to function more efficiently and effectively if we are presented with fuel and nutrients on a regular basis. Most of us do well on three moderate meals, starting with a breakfast, and perhaps including the odd small snack. The pace of life can sometimes mean that some of our meals are more easily overlooked than others. If meal planning for regularity is a concern for you then it may be most helpful to explore practical ways to manage your meal gaps before anything else.

CHECK 2 - VARIETY

Are you eating a mix of nutrient rich foods at most meals? Each food we eat carries its own range of nutrients so we need to eat a variety of foods from the different food groups each day. If you have a whole food group missing from your regular food choices, try to find foods in that group that you enjoy and eat them more often.

Protein Choices from:

- Animal sources such as meats, fish (white and oily), eggs, cheese, milk,
- Vegetable sources such as beans, lentils, nuts and seeds.
- Most of us eat sufficient protein but perhaps limit our range of sources. Try to include a protein choice at each meal.

Carbohydrate Choices from:

- Vegetables and fruits. Most of us have too few of these. Go for generous portions vegetables and salads with moderate amounts whole fruits and only small amounts of juices. Choose a rainbow of colours for nutrient value and eye appeal.
- Grains and white potatoes. Most of us have very generous portions of these so it's a good idea to broaden your variety and consider your portion sizes. Try choosing the less processed options more often, such as wholegrain breads, pastas and cereals. Consider swapping white potatoes for sweet potatoes or a mix of roots (celeriac, swede, carrots etc) at some meals to boost nutrient value.

Fats & Oils from:

- Vegetable sources such as olive oil (high in monounsaturated fats; a good main choice), other nut and seed oils (high in polyunsaturated fats; use in small amounts), whole or ground nuts and seeds, avocados.
- Animal sources such as butter, egg yolks, oily fish, meats.
- We all need to include some good quality fats and oils in our meals, they are essential for health.

CHECK 3 - STABILITY

Are you helping your body to keep blood glucose levels stable? Consider your food combinations at meals and snacks. By choosing more moderate portions of carbohydrates and teaming these up with a source of protein and some fats or oils we can help to slow down the release of glucose into the bloodstream.

This is readily described as lowering the glycaemic load (Lower GL) and may provide us with better blood sugar and weight control, improved blood lipid profiles and more sustained energy levels.

The following meal-building suggestions may start you thinking of new food combinations you may like to try. Just keep things simple and explore changes, one at a time.	
Breakfast	<p>Choose a good Protein Choice e.g. eggs, beans, bacon, ham, mackerel or nut butters.</p> <p>Include Vegetable Choices such as tomatoes, mushrooms or salads to give colour, crunch and a nutrient boost. Cook or dress these with your favourite oils.</p> <p>Include a moderate portion of a Lower GI Carbohydrate Choice such as wholegrain granary bread, stoneground wholemeal bread with whole seeds or sourdough breads...with butter.</p> <p>OR</p> <p>For a cereal option, try a Lower GI Carbohydrate Choice based on wholegrain oats e.g. porridge</p> <p>Moderate the cereal portion and boost the protein, fat and nutrient value by adding nuts, seeds, unsweetened yogurt or milk. Add moderate portions of fruit (eg berries) to sweeten and boost nutrient variety further.</p>
Meal Mix	<ul style="list-style-type: none"> • Vary your Protein Choice e.g. meats or white fish or oily fish or beans or eggs or cheese • Add Vegetable Choices. Experiment with colour variety and texture; crunchy vegetable sticks, rainbow salads, chunky vegetable soups, stir fries and roasted vegetable mixes. Cook or dress these with your favourite oils. • Add a Lower GI Carbohydrate Choice e.g. pasta, noodles, brown basmati rice, sweet potatoes, wholegrain granary / seedy type or stoneground wholemeal or sourdough breads or oatcakes. • Dessert: choose fresh fruit and whole milk yogurts more often
Snack Mix	<ul style="list-style-type: none"> • Fresh fruits including berries • Nuts and seeds • Yogurts (preferably whole milk based and unsweetened) • Oatcakes with cheese • Vegetable sticks with houmous, yogurt based dips or pate • Plain dark or milk chocolate - in moderation
Drinks	<ul style="list-style-type: none"> • Water (Add a citrus slice or cucumber and mint leaves to ring the changes). • Tea, coffee, herbal / fruit teas (no added sugar) • Unsweetened milk (dairy, soya, nut milks etc.) • Sugar free flavoured squashes / waters etc.

NOTE: If you are a diabetic on insulin or taking medications to help lower your blood glucose levels, please have a word with your medical team before making significant changes to your glycaemic load. Your medicine doses may need adjustment.

WHAT DO LOWER AND SLOWER CARBOHYDRATE MEALS LOOK LIKE?



BBC EVERYDAY GOOD FOOD: LOW CARB COOKING

Good as a starter just to get ideas; small, cheap and colourful with inspiring pictures. Aimed more at the low carb weight loss market so extra fats readily need to be added to make these recipes more ketogenic. All recipes counted for carbohydrate, protein, fat and calories.



THE REAL MEAL REVOLUTION - PROF TIM NOAKES

Simple but inspirational. A MUST for adults!



THE LOW CARB GOURMET - KAREN BARNABY

Good for grown – up ideas. Lovely recipe ideas. All recipes counted for carbohydrate, protein, fat and calories.



THE POWER OF THREE - DALE PINNOCK

Simple recipes to help to slow down the effect of carbohydrate on blood glucose levels and include good fats in meals. Not specifically 'ketogenic' but many recipes are suitable and could be adapted.



GOOD + SIMPLE - HEMSLEY & HEMSLEY

Inspirational UK book on using simple nourishing foods. Not specifically 'ketogenic' but many recipes are suitable.





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