Introduction and preparation for Medical Ketogenic Therapies in children
Introduction

The ketogenic diet is more than its title suggests – it is NOT some fad diet that is currently ‘fashionable’. It is a proven medical therapy for epilepsy based on a diet that is high in fat, adequate in protein and low in carbohydrate. It MUST be managed by a qualified ketogenic dietitian in partnership with a neurologist/doctor. It is clinically proven to be highly effective in managing difficult to control epilepsies, as well as metabolic disorders such as GLUT1 deficiency, with research currently being conducted looking at the diet as a therapy for a range of long term neurological diseases and cancer.

History

The diet was first developed in the USA in the 1920’s and was used for children and adults. With the advent of newer anti epileptic medication in the 1930’s-1970’s interest in the diet waned. The 1990’s, however, saw a resurgence of interest in the diet for children. In the 1970’s the MCT (medium chain triglyceride) version of the diet was also introduced. Early 21st century saw development of alternative more relaxed modified variants of the traditional ketogenic diets, as explained further on in this booklet.

Our beautiful cover girl is Parys, who has Glut 1 Deficiency and has been on ketogenic therapy for many years.

The information contained in this booklet has been checked and approved by the Matthew’s Friends Medical Board and was correct at the time of writing.
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Ketogenic Therapies

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 MCT oil or emulsion is included with each meal/snack. This enhances ketosis and allows a more relaxed carbohydrate restriction.

- **Modified Ketogenic Therapy** – Originally developed in the USA and termed the Modified Atkins Diet, this is careful on protein foods and requires measurement of carbohydrate foods and adequate portions of fats at meals.

- **Low Glycaemic Index Treatment** – very similar to the Modified Ketogenic Therapy 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 feed and specific formulas are available.

How the diet works

There is much research in this area. The diet appears to "mimic starvation" by using fat as an alternative fuel source for the body, producing ketones. These ketones and the associated biochemical changes in the brain, can have an anti-convulsive effect.

The "Holy Grail" of the ketogenic diet is for a patient to be initiated on the diet, become seizure free, reduce/remove the amount of anti-epileptic medication taken, wean the diet off after a period of 2 years and STAY seizure free. This DOES happen for some, but there are also other degrees of success on the diet:

- **Reduction in number of and intensity of seizures**
- **Reduction in drugs and their subsequent side effects**
- **Increased alertness**
- **Improvement in behavioural problems**
- **Improvement in learning ability**
- **QUALITY OF LIFE!**

Fears and misconceptions

Arguments against using the diet usually consist of the following:

**"The diet is difficult"**

It depends what you mean by “difficult” – it’s difficult to watch your child seize. It’s difficult to watch your child in a drugged up haze. It’s difficult to feel that you’ve “lost” the child you once had to seizures. Compared to these, spending time in the kitchen, actively involved in your child’s care can actually be extremely rewarding. We don’t want to underplay the amount of effort needed to calculate or administer the diet – initially you can feel like you’re never out of the kitchen and it can be a daunting prospect but we just want to put this effort in context.

**"It is unpalatable"**

ALL forms of these dietary therapies are high fat, adequate protein and low in carbohydrate and in the early days of the diet the above was true – cups of oil had to be drunk and spoonfuls of butter needed to be eaten – that is NOT the case anymore. As much as possible we work from the usual meals made at home although in some instances, we do have to change some of the ingredients to make the meal more ‘ketogenic’. There are a lot of good ketogenic recipes available now, with a huge assortment on the Matthew’s Friends website that you can download. Your dietitian will also be a great help with meal planning and recipes.

**"It Won’t Work for Everyone"**

That is true – sadly the diet doesn’t work for everyone, but it does have a good success rate for drug resistant epilepsies, as good as any new anti-epileptic drug that is currently on the market and remember, the drugs don’t work for everyone, VNS won’t work for everyone and surgery is not always an option for a patient. If the first two appropriate medications fail to control the epilepsy, the chance of a 3rd medication working is reduced to approximately 12% and a 4th medication is then reduced to approximately 5%. We can usually tell within 3 months whether a ketogenic dietary therapy is going to be helpful or not.

**"The positive effects may not last"**

You may be told that "only rarely do the effects last more than 12 months" – many can testify that this is often not the case, and if things do go downhill then the diet may need fine tuning and your dietitian will offer expert advice on this as you go along. Breakthrough seizures can be treated by changing the ratio, the calories, the timing/size of meals/snacks, changing the diet format as well as drug weaning.

Please note:

- That any type of Ketogenic Dietary Therapy should only be undertaken with strict medical supervision by an experienced team.
- As development of these dietary therapies are continuously being updated and new information and research being carried out, please visit our website or contact our office to receive further and more detailed information on these types of therapies.
Preparation of your child and your family for ketogenic therapy... 

A considerable change to your child's eating habits....

A ketogenic diet generally involves quite a significant shift in food choices and the way your child's meals will look. To ease your child into this, it would be wise to discuss with your dietitian a possible '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.

Obviously there are some cases where this will not be possible as your child may need to be started on ketogenic therapy quickly or as an emergency. Although you may have to start with some very limited recipes and meal choices, it won't be long before you will be able to extend the range of meals you can provide. Your dietitian will be there to guide you through this.

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 your child as well as packed lunches for school. However, there are plenty of recipes available which can be 'batch cooked' and frozen so you will not be chained to the cooker – even if it does feel like it in the early days.

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 need to keep daily records of your child's:

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

You will need to e-mail or post a summary of this information to your child’s managing team and you are usually provided with a weekly monitoring form to complete. During the initial stages of treatment, your child's diet may need more frequent adjustments to achieve optimum effect and maintaining accurate daily records is essential for this process.

Positive support from Family and Friends for both your child and YOU!

A radical change to your child’s eating habits can be tough under any circumstances but ketogenic therapy is much more than this. YOU become responsible for delivering your child’s 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 child’s treatment and will work alongside and support you. Moral and practical support from those around you is SO important and makes a real difference.

Support for your child is also hugely important, they might try to fight against the diet or change their mind about wanting to be on the diet and all this can be very stressful. They might not fully understand why they can't have the same chocolate cake as everyone else or can't just help themselves to the snacks in the fridge anymore. Matthew’s Friends have produced a booklet called ‘I am going on a Ketogenic Diet’ which explains the diet in an easy to understand way for children – this may be useful in your situation and this booklet is freely available to download or we can send a copy to you.
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What do YOU consider failure/success using the diet?

This is an important question to think about, for some families, complete seizure control, no medications and back up to speed at school or college is success, anything less than that is failure. For others, they just want their children to be off medications (or at least reduce them) or they want their children to feel better and have a better quality of life. A 50% reduction in seizures for a child who is having hundreds a week can be a massive change for them, is it a success or a failure though? It all depends on what your expectations are for the ketogenic diet.

Be REALLY honest with yourself as to what your expectations are. Deep down, there is no question that we all hope for complete seizure control, no medications and an end to the nightmare and for some, that dream WILL come true. For those who have children with very difficult to control epilepsy or have some catastrophic type of epilepsy syndrome who have gone through years of medication, seizures and hospital visits, it may be wise to lower your expectations at first and take it a step at a time. Try not to set yourself up for disappointment and keep an open mind.

We are not encouraging you to be pessimistic, but we are asking that you be realistic, and do try to focus on ALL the possible benefits of the diet. Remember that the diet is not necessarily forever (depending on the syndrome/condition that is being treated) in most complex epilepsy cases, we would look at the diet being in place for about 2 years and it will be fine tuned and changed during that time as well. It certainly goes faster than you think and a successful diet is very much worth the time and effort you put into managing it.

If you would like to read inspirational stories then please visit our website for ‘keto stories’ to read how others managed their ketogenic therapy.

Some important things to think about for you and your child...

Commit yourself, your family and your child for at least three months to ketogenic therapy.

This is not a long period of time and it is needed in order to initiate the diet and for your dietitian to fine tune it to a level where you will be able see whether ketogenic therapy is beneficial to your child or not. For some, this process may take longer and benefit may not be seen until some medication has been weaned. Each child is an individual and your medical and ketogenic team will manage the therapy and the changes WITH you. If some benefit has been seen at 3 months the diet will remain and your child’s neurologist will usually look at starting to wean medications. Some children are able to wean off all medications and some children need the diet as well as some medication. Under no circumstances should you wean any medications without first consulting with your child’s neurologist.

If, at the end of 3 months, things have sadly not gone well and there has been no positive affect with the diet, then at least you can be confident that you gave it your very best and did everything correctly. We have difficult enough decisions to make in any event without punishing ourselves with ‘if only I had done this’ or ‘I really didn’t do that correctly and if I had, would the diet have worked?’ If you know that 100% commitment was given to the diet and sadly it didn’t work you can move on from it and try a different treatment.
How is your child’s school going to react? Are they going to be supportive?

Communication is the key to making this work with your child’s school and they really must be supportive so that you can have peace of mind when your child is at school. Make sure that they have as much information as possible and are very clear that this diet is a medical treatment and MUST be treated with as much respect and importance as a child needing to take medication. Their food IS their medicine.

Some issues that can arise in certain schools:

1. ‘No nut’ policy

There are quite a few ketogenic recipes that use nut flours instead of wheat flour when making baked goods, so find out what the policy is for your child’s school. Discuss with them whether there is any way that this can be overcome or managed so that no child is put at risk who has a nut allergy but also your child is able to enjoy their food and not have to miss out on the foods that make the diet easier for them.

There are many ‘nut free’ recipes available so please discuss this with your dietitian and also check the recipes on the Matthew’s Friends website.

2. No ‘re-heating’ policy

Some schools won’t allow meals from home to be re-heated at lunchtime for your child, so it may mean you have to plan for cold packed lunches to be sent in every day from home.

Some families use Food Flasks to keep things warm for lunch, but these are not ideal in our opinion. We would recommend that you discuss this option with your dietitian in the first instance.

3. Adequate supervision around food

The school staff and lunchtime helpers have to be aware that your child must not eat anyone else’s food and no other child may eat your child’s food! More supervision may well be required at meal times to ensure that this doesn’t happen.

Although most schools try to have a ‘healthy eating’ policy, there are times when there are parties, special occasions and fund-raisers going on when lots of different foods will be available. The school need to communicate these times to you well in advance if possible so that you can arrange a ‘ketogenic’ version to be made available. This will help your child to feel included with the rest of the class. Matthew’s Friends have designed stickers that can be used on lunch boxes, bags and clothing, these are freely available and a stock of them can be sent to you when you need them.

Respite Centre

If your child goes to a respite centre, you may encounter the same worries and difficulties you have to overcome with your child’s school. Once again communication is the key to making sure that not only does your child have a nice time and the diet is adhered to, but you have peace of mind and can enjoy your respite time too.

“Matthew was on the diet for nearly 6 years and yes, there were certainly days when I could have cheerfully thrown the scales out of the window but looking back now I certainly wouldn’t have changed it and yes, it was all worth it. For some reason Monday evenings turned into my ‘batching night’ and I would put my little TV on in the kitchen or listen to an audio book whilst making quiches, muffins and cookies and before I knew it I had a freezer full and it would be another two weeks before I would need to make another lot. Sometimes the thought of doing it was worse than actually doing it”

Emma Williams MBE, mum to Matthew
Food changes

A summary of the key food changes involved

Your child’s dietary prescription is designed around their specific nutritional requirements, based on their growth requirements, activity level, normal diet and any nutrient deficiencies that may have emerged from their 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 you will be guided on how much to include at meals and how to spread this throughout the day by your child’s dietitian.

We recommend choosing carbohydrate containing foods that release their energy more slowly such as non-starchy vegetables, berries, dairy products, nuts and seeds to provide your child’s prescribed amounts at meals. Weight for weight, these foods are also much lower in carbohydrate than traditional starchy sources of bread, rice, pasta and potatoes. You will get a bigger portion 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 child’s main fuel; needing to be included in each meal and snack. Examples of good fat sources are oils, butter, double cream, mayonnaise, avocados, nuts and cream cheese. Protein containing foods such as meats, oily fish and cheese in your child’s 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 child’s prescription will provide you with guidance on how much to use and when. Amounts will depend on your child’s body weight and growth requirements, day to day activity levels and whether there is a need for weight maintenance, weight reduction or weight gain.

Protein containing foods

Depending on which version of the ketogenic diet your child is on, you will be advised on how much to include with each meal. On modified therapies protein foods are not usually weighed and measured but large portions can deliver much more protein than the body needs. The excess is burned to provide energy. This reduces the need for your body to burn as much fat; impairing ketone production. Again your child’s dietician will provide you with guidance on how much to give.

Vitamin, mineral and micronutrient supplements

Baseline vitamin, mineral and trace element supplementation is generally recommended alongside ketogenic therapy and there are some ketogenic versions available on prescription that your child will need to take alongside their diet. Your dietician will advise you of how much to give and arrange to have these available on prescription.

Are there any side effects to ketogenic therapy?

During initiation

As your child’s ketogenic diet is stepped in, their metabolism takes a few days to adjust and this may lead to tiredness, irritability, a mild headache or slight nausea. This is quite normal and should clear after a few days. Keep a careful eye on your child during diet initiation and if you are worried about anything then contact your dietician.

We advise YOU to take it as easy as possible during the introductory week of your child’s ketogenic diet. Eat everything at home as much as you can so you can concentrate on learning the diet and becoming familiar with what you need to do. It will also give you time to think about your child’s new food choices and meal preparation and how you can try to fit it in with the family’s meals.

Changes to your child’s digestion

A ketogenic diet can alter your child’s digestive processes and the availability of food and fuel to the millions of bacteria living in the 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 larger portions of very low carbohydrate vegetables and perhaps including ground flax seeds or psyllium husk in some of your recipes. Sometimes your child’s doctor will need to prescribe a stool bulking agent such as Movicol which may be helpful as a regulator in the early stages while their system adjusts.

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 child’s fuel intake is greater than their needs. When their weight is increasing unnecessarily they will not produce ketones as effectively, leading to lower levels.

Unplanned weight loss will occur if your child is not managing to eat all their required fat portions. Once their body has switched into fat burning mode, it will burn the fats they eat, and if not enough fat is eaten, then the bodies fat stores will be mobilised and burned. This will lead to weight loss, feeling tired and ketone production may be impaired or exaggerated depending on their individual response. Their prescription will be designed to match their needs and you are usually asked to weigh your child regularly (at the same time of day) on digital scales and send this information to your dietician. Your dietician will fine tune the diet so as to meet the exact requirements of your child.
First steps towards ketogenic therapy

Before you approach ketogenic therapy, it is worth looking at the ‘Eating for improved health and wellbeing’ information on our website to see if there may be some simple but positive meal adjustments you can try not only for your child, but for the whole family whilst you wait for your referral to a ketogenic dietary centre.

As your child gets closer to their start date for dietary therapy you can also look at trying the following:

- Stop all cakes, biscuits, sweets and chocolate and swap these snacks for protein ones such as sliced ham, cubes of cheese, pieces of chicken etc.
- Swap full sugar varieties of drinks with sugar free (look on the label for trace carbs or less than 0.6g per 100mls) ones that you can use on the diet.
- Sugar free jellies – try them and put some double cream into them as a milk type jelly to use as a pudding.
- Swapsugar for zero calorie sweeteners (the ones recommended by your dietitian).
- Try different vegetables and experiment. Use celeriac (celery root) as you can use this like you would potatoes and it is extremely tasty.
- Have bacon and egg for breakfast or an omelette instead of cereals.
- Put butter on your child’s vegetables or meat.
- Make some creamy sauces to go over your child’s dinner such as a simple one made with double cream, mushrooms and butter.

Don’t weigh anything at this stage or cut portion sizes just try some of these simple suggestions that will help prepare for ketogenic therapy.

If you can do a ‘test’ period then this will make life easier for you. Your dietitian can make sure that the foods your child likes on the ‘test period’ can be incorporated into their ketogenic diet and it will help your child realise that they will still be able to eat lovely food whilst on ketogenic therapy.

You will have to weigh things out at every mealtime, this will get easier with practice and you will find that you do have to be organised and as your confidence grows so do your organisational skills!

REMEMBER – YOU DO NOT HAVE TO BE A CHEF TO MAKE THE DIET TASTY, PALATABLE AND EASY TO DO – but it will take a little time for you to feel comfortable with things. Keep it simple to start with and as your confidence grows – so will your menus!

Recommended equipment:

Please make sure you visit our website shop and order your free starter pack from us, which contain the essential equipment listed below as well as some additional ketogenic samples. We would like to thank all our fundraisers who make this possible for us to support the families and children.

(Please note that these are freely available to families in the UK and Ireland under supervision of a ketogenic dietitian and are subject to availability).

Essentials:

Electronic scales

Make sure these can weigh quantities to 1 gram.

If you decide to continue with the diet beyond 3 months, it might be worth investing in a set that weighs to 0.1g. The reason is that it is more accurate. You will find that weighing very small amounts can be difficult (although not impossible) on a basic model. It is not a big problem, but as you continue and your confidence grows, you may wish to incorporate foods where you only need 1.5g of something (e.g. sesame seeds) and accuracy becomes more important. Some of our families that use the EKM (Electronic Ketogenic Manager) meal planner only use 1.5g of an ingredient and again this is where a more specialist type of scale would need to be used.

Also note the maximum weight your scales go to as you may wish to weigh the ingredients in the actual pan you are using to cook with, we would advise that you get one that CAN manage this.
Setting up your ketogenic kitchen:
A brief guide to store cupboard basics

Flaxseed and Psyllium Husk based products
Ground flax seeds can be very helpful in baking ketogenic breads, pizza bases, porridges etc. They are high in fat, contain protein, but are very low in carbohydrate. You can buy the seeds and grind them as you go (the best way to preserve the essential fatty acids) or buy ready ground flaxseed or flaxseed and nut mixes (store in the fridge after opening). The Linwoods brand offer a wide range of products that are available from health food stores or online. Some of the low price supermarkets do their own versions of these, but some of the mixes can be higher in carbohydrate so please check labels. We recommend going for the lower carbohydrate options.

Psyllium husk is a fibrous substance that can be very useful as a dry ingredient in baking and as it is not absorbed it does not count as a carbohydrate so can be used freely. However, make sure you buy the whole husk and not the pre-ground or powdered husk as some of these can contain carbohydrate and the pre-ground husks have a tendency to turn your baked goods a purple colour. Always check the labels and aim to buy the whole husk. A good brand of Psyllium husk that we have used in our ketokitchen is from BuyWholefoodsonline.co.uk.

Note: It is very important to ensure that adequate fluids are taken when introducing or increasing flaxseed or psyllium husk. Always make sure you discuss using these products with your dietitian, who can give you guidance as to appropriate quantities.
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**Herbs, spices, stocks and flavourings:**

Use the following to add delicious flavours and variety to your meals:

- **Herbs:** Dried and fresh. If you are using large amounts of fresh herbs, check the carbohydrate content as this may need to be counted in to the meal.
- **Spices and curry powders:** Dried. Check labels of ‘mixes’ for added sugars or flour.
- **Commercial stocks:** Look for lowest carbohydrate versions; try Kallo organic vegetable stock cubes or Knorr touch of taste liquid.
- **Homemade stock is still the best:** Don’t let bones go to waste. For further tips look at [http://nourishedkitchen.com/bone-broth/](http://nourishedkitchen.com/bone-broth/)
- **Savoury spreads and flavours:** Bovril, Marmite, Worcestershire sauce, mustard, vinegar, a dash of soya sauce.
- **Lemon and lime juices:** A squeeze or two is fine but if you are using these in volume – likely best to count the carbohydrate into your meal.
- **Sweet enhancers:** Small amounts of essences e.g. vanilla essence.
- **Da Vinci flavoured syrups** (contain sucralose) can be used in drinks and for cooking (available on the internet).
- **Joseph’s sugar free maple syrup** (internet).

**Milks and Creams**

Use unsweetened almond milk or unsweetened soya milk as these have much lower carbohydrate content than cows or goats milk.

Choose double cream, mascarpone cheese or Cornish clotted cream as these tend to have the highest fat content for the lowest carbohydrate content.

**Pasta replacements**

There are many brands and formats of products based on Konjac root. E.g. Slim Pasta or Miracle Noodle type products. They can add bulk to a low carbohydrate meal and provide a source of fibre but little else. They are available from health food stores or online.

**Jelly**

Sugar free jelly e.g. Hartley’s sachets (available in most supermarkets). Note this product contains Aspartame. Morrison’s ‘own label’ version is an alternative sweetened with Sucralose.

**Gelatine.**

**Sweeteners …… quite a minefield!**

Many choose to avoid sweeteners altogether. However, for those of you wishing to use something, we tend to recommend carbohydrate and calorie free options such as Hermesetas liquid (liquid saccharin) or pure Stevia powder products.

Be aware of the filler in powdered sweetener products as they are often carbohydrate based such as maltodextrin. However a base of inulin (a soluble fibre) as found in Nature’s Garden Stevia is classed as carbohydrate and calorie free.

Sugar alcohols (e.g. sorbitol, xylitol, maltitol) are not recommended to be used in the early months of ketogenic therapy. These contribute calories and may cause diarrhoea and stomach cramps if taken in larger amounts; tolerance varies!

So-called ‘natural’ sweeteners such as honey, agave syrup, molasses, maple syrup and fruit sugar (fructose) are concentrated sources of carbohydrate and must always be counted into your child’s prescribed amount of carbohydrate for a meal.

Check labels carefully and do ask your ketogenic team for guidance if you are unsure.

**Vegetables – the lowest in carbohydrate**

Choosing lower carbohydrate vegetables to make up a proportion of the carbohydrate allocation for a meal can really help to add bulk, phytonutrients and a larger surface area to dress with fats and oils. The following may be helpful:

- **Broccoli**
- **Cauliflower**
- **Celery**
- **Courgette**
- **Mushrooms** (these absorb fats and oils really well)
- **Mixed Salad leaves** (check nutrition label on packs – carbohydrate values vary)
- **Spinach**
- **Watercress**

It is worth using the baby versions i.e. baby corn or kale, being younger they have not had time to store carbohydrate, so tend to contain less.

**Yogurt**

Where possible go for Greek or Greek Style natural yogurts as these have a higher fat content but remember to check the carbohydrate content, as this may be 4-6g per 100g.

There are dairy free alternatives such as Coyo yogurt (plain) or Alpro plain soya or coconut yogurts available which are also lower in carbohydrate, but please always read the label and discuss with your dietician.
Suppliers:

A ketogenic diet is generally based on meals prepared from normal everyday unprocessed foods; meats, fish, eggs, cheese, vegetables, fruits, fats and oils, herbs, spices, nuts and seeds. Most regular ingredients can be found in your regular supermarket. Do shop around on price. The budget supermarkets such as Lidl and Aldi can be very good value for Greek yogurt, double cream, dark chocolate (with high cocoa content), nuts and seeds. Always check the individual nutrition labels as carbohydrate and fat contents will vary between brands.

For more unusual ingredients such as low carbohydrate versions of sauces, flours, bread etc, you may need to look further than your local supermarket. Try a local health food store or look on the internet for such items. These are not essential but can help to increase your range of meals and snacks, when you start to become a bit more adventurous!

http://www.lowcarbmegastore.com/
or https://www.carblife.co.uk/ for Joseph’s (sugar free) Maple Syrup (for adding to pancakes & porridge) and Heinz low sugar tomato ketchup.

http://www.healthysupplies.co.uk/ for ground nuts & tomato ketchup.

EKM
(Electronic Ketogenic Manager)

Bruce Carroll (MicroMan2000 Ltd) worked with Dr. Elizabeth Neal RD, at the Institute of Child Health in London to develop a ketogenic calculator back in the year 2004. This program allows dietitians and those parents and patients that wish to have ability to fine tune or even create meal plans with accurately calculated ratios, fat, protein and carbohydrate intake. It must be stressed that this NOT a substitute for a medically supervised diet.

This programme must be used with the close supervision of a ketogenic dietitian and medical supervision. It is available with all foods from “The Composition of Foods” data set (version 7), however any food can be entered directly into the programme thus EKM can be used with a personal selection of foods or a vast range from the data set provided.

The one stipulation that Bruce and Liz made when developing this programme was that it would be made available freely to any parent or patient that required it and was medically managed by a ketogenic team, that condition still applies today.

In partnership with Matthew’s Friends a new phase of development took place in 2016 and a major re-write of the EKM took place which enabled the program to be used within the following operating systems and platforms:

- Mac desktop OS X
- PC, Windows version 7 and above (Vista will work but not recommended)
- Android; phone and tablets (recommend non-Intel platforms)
- iPad and iPhone; IOS

Therefore the majority of desktop and portable devices are now supported by this new release of EKM and the EKM can be taken anywhere as you do not need to be ‘online’ in order to be able to use it.
Matthew’s Friends are delighted to be supporting the EKM and sponsoring its continuing development so as to benefit not only families but also ketogenic dietitians.

For those wishing to download EKM then you will need to confirm that you are being supervised by a ketogenic team.

Please contact ekm@microman2000.co.uk for your EKM access code and registration.

Tutorial films of how to use the EKM are available on the Matthew’s Friends website and a User guide is available to download or hard copies can be ordered from Matthew’s Friends.

For further information and support please visit the EKM website http://ekmketocalc.com/

Visit the Matthew’s Friends YouTube channel

Visit the Matthew’s Friends YouTube channel and learn how to use the Electronic Ketogenic Manager (EKM) to help successfully create Ketogenic recipes and manage a medical Ketogenic Dietary Therapy.

www.youtube.com/matthewsfriendsorg

Four films will help guide you through every step

EKM is a multiplatform Ketogenic calculator available from www.ekmketocalc.com
The story of Matthew’s Friends....

My son Matthew suffers with a catastrophic form of epilepsy called ‘Dravet Syndrome’ and his seizures started when he was 9 months old. I first asked about the Ketogenic Diet when Matthew was 2 years old, but I was told by his neurologist that the diet didn’t work and I was made to feel like a bad mother just by suggesting it.

So we battled on, trying innumerable medications which didn’t help Matthew’s seizures and which caused devastating side effects. I still tried to push for the diet but kept being told that it didn’t work and drugs were our best option. Five years later, when Matthew was having literally hundreds of seizures each week and we had run out of medication options, Professor Helen Cross began a research trial of the Ketogenic Diet at Great Ormond Street Hospital and thankfully our neurologist finally agreed to refer him and Matthew was able to try the diet.

Within 2 weeks of starting the diet Matthew’s seizures had reduced by 90% and within 8 months he was weaned off ALL medication. Sadly for Matthew, the damage had been done. Years of seizures had caused terrible brain damage, our family had broken apart and I was a single mum to Matthew and his younger sister Alice. For 6 years I weighed every gram of food that Matthew ate and YES, it was all very much worth it. Eventually I was brave enough to wean him off of the diet and the good effects of the diet are still with him today. The diet DID work and I got what was left of my son back.

Inspired by Matthew, I set up Matthew’s Friends in 2004. I knew that families were being told the same as I had been and it was WRONG. I couldn’t live with that.

Professor Helen Cross joined me by leading our Medical Advisory Board and together with 2 very close and supportive friends, the Matthew’s Friends Ketogenic Dietary Therapies Charity was launched to provide information, education, training, support and vital resources for all the families that were battling drug resistant epilepsy and wanted to know more about ketogenic therapy.
Matthew’s Friends Today

I am so proud of how far this little charity has come and I am extremely fortunate to work with such a wonderfully dedicated team, who are so passionate about what we do. We invest considerable funds into clinical research, as well as our training and educational programmes not only for families but professionals too. We provide free starter packs and ketogenic samples to families throughout the UK and Ireland, as well as a recipe development service and online tutorials via our Ketocooking channel and practical information booklets such as the one you are reading now. All our information and resources can be freely downloaded from our website or hard copies ordered from our office.

We provide funding for numerous NHS centres around the UK so that they can either expand their existing ketogenic services or set up new ones. 2011 saw the registration of Matthew’s Friends in New Zealand and we also opened our own treatment clinic here in the UK where patients can be referred if there is no local service available to them and where we also carry out ketogenic research projects. 2014 saw the registration of Matthew’s Friends in Canada.

We have also expanded our remit to help adults that are failing anti-epileptic medication and we are now working in the field of certain types of brain cancer and metabolic disorders such as Glut 1 Deficiency. In 2016 we launched our annual KetoCollege training programme for healthcare professionals who want to provide ketogenic therapies for their patients.

Professor Helen Cross is still with us too, she leads not only our very distinguished medical advisory board but also our clinical team and our Ketocollege course for professionals.

For over 16 years now the ketogenic diet has taken over my life and I absolutely love what I do. Some days can be frustrating and some very painful especially when you hear about someone suffering, but when you also hear about a child or an adult getting better and enjoying their life again... There is no better feeling. Running the Matthew’s Friends telephone support line means I get to talk to wonderful, brave and inspiring families every day. You never cease to amaze me and if Matthew’s Friends can help in any way then don’t hesitate to pick up the phone, email us or message us via facebook or twitter. You are NOT alone with this and if you ever feel like you can’t do it, trust me... YOU CAN. We look forward to being here to support you and your family and GOOD LUCK on your own ketogenic journey.

With very best wishes,

Emma Williams MBE
Ketocollege is a training course for Medical Professionals working with Medical Ketogenic Therapies, for further information please contact ketocollege@mfclinics.com