

INTRODUCTION TO MEDICAL KETOGENIC THERAPIES FOR CHILDREN



MATTHEWS FRIENDS

Ketogenic Dietary Therapies

Information • Training • Research • Support

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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.

INTRODUCTION

The aim of this booklet is to help prepare you and your child for Ketogenic Dietary Therapy, to take away some of the 'mystery' surrounding it and give you more confidence as you move forward.

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 Classical Ketogenic diet was first developed in the USA in the 1920's and was used for children and adults. With the advent of newer anti seizure medication (ASM's) in the 1930's-1970's interest in the diet waned and in the 1970's a specific type of fat called MCT (medium chain triglyceride) was introduced into these diets. MCT fat is particularly good at making ketones. However, in the 1990's there was a huge resurgence of interest in the diet for children and in the early 2000's modified versions of the traditional ketogenic diets were developed. These modified ketogenic diets are a little less strict than the traditional versions and are often used for children and adults.

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.

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.



KETOGENIC THERAPIES

There are 4 main types of ketogenic diet (or 5 if counting MAD and MKD separately?!) There are many factors that influence the choice of ketogenic diet. Your/The dietitian/keto team will discuss the options with you and guide appropriately.

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 slightly more generous carbohydrate allowance to be given.
- **Modified Ketogenic Therapy** – originally developed in the USA and termed the Modified Atkins Diet, allows moderate protein intake and requires measurement of carbohydrate foods and fats.
- **Low Glycaemic Index Treatment** – is 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. The GI index of a carbohydrate food indicates how quickly it is absorbed into the blood. The lower the index the smaller the impact on blood sugar levels.

Ketogenic dietary therapies can be taken as a normal oral diet, via an bottle feed, or tube feed. Specialist medical formula, supplements and foods 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-seizure medication taken, wean the diet off after a period of 2 years and STAY seizure free, so it is important to consider your expectations of ketogenic diet therapy. 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**



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 – this 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-seizure medication 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 changes to the diet or Anti Seizure Medication might need to be considered. Your Keto Team will work with you and guide you through any changes.

PREPARING YOUR FAMILY AND YOUR CHILD 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 4-6 week preparation phase where you begin to reduce the high sugar and high carbohydrate foods and try keto friendly food. This will help to build your confidence in your child's acceptance of keto friendly foods.

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.

CAREFUL RECORD KEEPING:

The value of this cannot 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
- weekly weights

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 big 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 giving it the best chance of being successful. This can be both empowering and worrying in equal measure. There may be days when you need help with shopping and cooking 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. 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.



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 to see whether ketogenic therapy is beneficial to your child or not. For some, this process may take longer as 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 continue and your child's neurologist will usually look at starting to wean a medication. Over time, some children are able to wean off all medications. However, 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 effect with the diet, then at least you can be confident that you gave it your very best and did everything you could. 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, then you can move on from it and try a different treatment.





WHAT DO YOU CONSIDER A SUCCESS OR FAILURE WHEN 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 child 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 a catastrophic epilepsy syndrome such as Dravet or Lennox Gastaut, it may be wise to lower your expectations at first and take it a step at a time. A 50% reduction in seizures would be a great realistic target to start with and anything more than that, a bonus. 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 not just seizure control alone. Remember that the diet is not necessarily forever, the duration will often depend on the syndrome or condition being treated. However, 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.

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, 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. Your child's dietitian will calculate an individualised KD prescription for your child and guide you on their protein, fat and carbohydrate allowance to be divided amongst meals and snacks. 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.

CARBOHYDRATE CONTAINING FOODS - A SIGNIFICANT REDUCTION

We want to encourage the body to switch its fuel from the usual glucose produced from the breakdown of carbohydrates to ketones produced from the breakdown of fat. Limiting carbohydrates is fundamental to encourage this shift in fueling.

We recommend choosing carbohydrate containing foods that release their energy more slowly such as non-starchy vegetables, like broccoli and cauliflower, low carbohydrate 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. As such they should need 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 enough 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.

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 so it is important we achieve the right balance.

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 dietitian will advise you of how much to give and arrange to have these available on prescription.

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 SOME 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. The reason behind this is that they don't always keep food as hot as it should be and there could be an increased risk of food poisoning, especially if meat products are being kept warm. 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. Talk to the school about them giving you ample notice of these occasions 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.



RESPIRE CENTRE

If your child goes to a respite centre, you may encounter the same worries and difficulties that 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



Emma Williams with Matthew and his sister, Alice.

ARE THERE ANY SIDE EFFECTS TO KETOGENIC THERAPY?

DURING INITIATION

As your child's ketogenic diet is introduced, 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 dietitian.

We advise YOU to take it as easy as possible during the introductory week of your child's ketogenic diet. Clear the home diary 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 or dietitian will need to prescribe a suitable keto friendly medication to ease the situation 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 body's 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 dietitian. Your dietitian will fine tune the diet as needed to meet the exact requirements of your child.



FIRST STEPS TOWARDS KETOGENIC THERAPY

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.
- Swap sugar 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. Broccoli, cauliflower, spinach, kale and mushrooms are particularly low in carbohydrate so try to introduce these to your child's diet if not already consuming.
- 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 or a melted down full fat cream cheese.
- Try a low carbohydrate nut milks or alternatives in place of cows milk. As these types of milks move forward your dietitian will advise which milk is the best to try. The aim here is to experiment

Don't weigh anything at this stage or reduce 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.

When on KD you will have to weigh things out at every mealtime, this will get easier with practice. 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 contains 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 with preparing for ketogenic diet.

(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. flax 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.



N.B. For scales to weigh accurately they should be on a completely level surface and well away from televisions, radios, mobile phones etc, also it's a good idea to spray them with an anti static spray occasionally. If you decide to get yourself a better quality set of scales than your basic starter one, then consider getting one with a mains adaptor instead of relying on batteries.

Use the scales before starting the diet and familiarise yourself with them. It is always a good idea to feel comfortable with your equipment beforehand. When you first use them (or change the battery), turn them off and on a few times beforehand, as you may find that if you leave something on them for a while the weight seems to increase. Weigh your ingredients and then take them off the scales, don't keep going back to them – you will only worry if the weight has increased.

SETTING UP YOUR KETOGENIC KITCHEN

SPARE BATTERIES FOR YOUR SCALES

ALWAYS make sure you have a spare set of batteries in the house or even 2 sets, and immediately go out and buy a replacement set when you have used one of them. Don't believe the 'battery low' signal – it really means 'battery gone'. Panic WILL grip you if you are in the middle of weighing a meal out!

SMALL PLASTIC SEALED BOXES AND FREEZER BAGS

You can batch meals up and freeze them to use at a later date. Only buy small boxes or the amounts will look pitiful and they will also take up a lot of unnecessary room in your freezer. Freezer bags are also very useful when wanting to weigh specific portions of an ingredient such as meat or fish.

PLASTIC OR SILICONE SPATULAS

A couple of these are a good idea. These ensure that you can scrape every last bit out of the bowl or pan you are cooking from.

SMALL FRYING PAN

Doesn't have to be an expensive one – but does have to be non-stick.

SMALL PLASTIC BOWLS

Use these to replace the large bowl for the scales. The amounts of food you will be weighing will look very small in those large bowls and it is easier to scrape out a small bowl than a large one.

FREEZER LABELS AND PERMANENT PEN

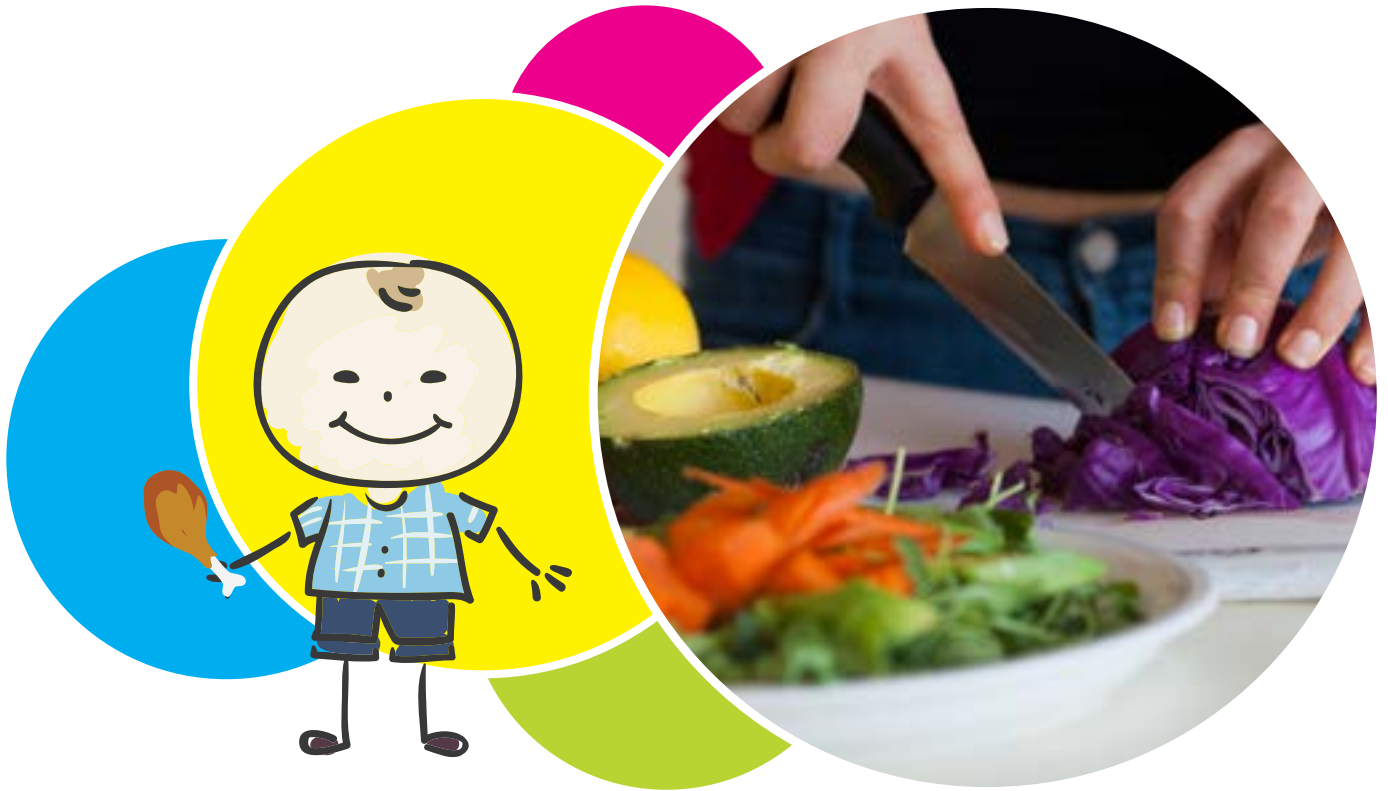
Good for your plastic containers and your freezer bags. Write down what meals are contained in them, the date and if anything needs to be added.

SILICONE MUFFIN MOULDS

These are excellent for baking small quantities as well as ketocakes and quiches. Being Silicone you won't lose any fat content in paper casings when baking muffins and if you leave the cakes to cool in the mould then any fat that may leak out of the mixture will be absorbed back into the food.

MEASURING SPOONS

Some ketocentres use measuring spoons to measure out portions of different foods, so these are always handy to have in the cupboard. Make sure the measuring spoons are the correct measurement for your country of residence.



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 own ketokitchen is from [BuyWholefoodsonline.co.uk](https://www.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.

HERBS, SPICES, STOCKS AND FLAVOURINGS

Some of the following can be used freely in meals to add variety and flavour. If you have any doubts though, please consult with your dietitian.

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 the lowest carbohydrate versions you can find. Knorr Touch of Taste liquid and their gel pots are quite useful but there are also supermarket own brands available too and don't forget to check the gluten free section of your supermarket.

Homemade stock is still the best Don't let bones go to waste. For further tips look at <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.

Sugar free/polyol syrups such as Da Vinci syrups or Flavdrops

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.



MILKS AND CREAMS

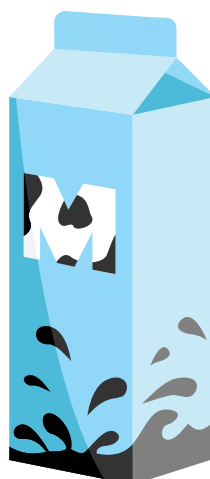
Use unsweetened almond milk or unsweetened soya milk as these have much lower carbohydrate content than cows or goats milk.

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. Eg. Slim Pasta or Miracle Noodle type products.

They can add carbohydrate free bulk to a keto meal and ensure your child can still have family favourites like spaghetti Bolognese, carbonara, lasagne etc with some keto friendly adjustments.



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 Truvia Powder, Stevia Powder or Liquid and Natvia.

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 Natures 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 to these can vary!

So-called 'natural' sweeteners such as honey, agave syrup, molasses, maple syrup and fruit sugar (fructose) are concentrated sources of carbohydrate and should be avoided.

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 vitamins and minerals.

The following may be helpful:

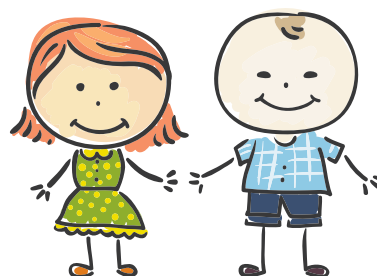
- **Aubergine**
- **Broccoli**
- **Cauliflower**
- **Celery**
- **Courgette**
- **Mushrooms (these absorb fats and oils really well)**
- **Mixed Salad leaves (check nutrition label on packs – carbohydrate values vary)**
- **Spinach**
- **Watercress**

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 yogurt as these have a higher fat content but remember to check the carbohydrate content, as they will contain some carbohydrate.

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



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, sugar free syrups and low carbohydrate pastas. 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 online 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 and help to replace missed foods like bread, rice and pasta.

<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

LOW CARB FOOD SUPPLIERS:

Consider adding seriously low carb bread

www.seriouslylowcarb.com

and

www.lowcarbfood.co

www.eatwater.co.uk



KETOGENIC MEALPLANNERS:

There are quite a few mealplanners available which can make the management of a Ketogenic dietary therapy a lot easier and help with flexibility of menus and recipes. We have featured 2 here, the Build a Keto Meal is a simple version which very is visual showing the actual portion sizes you will be working with and this is a good place to start for most families.

When you become more confident, you may wish to move on to a more specific type of mealplanner such as the EKM where you will be working calculating the numbers for your own recipes and inputting your own ingredients, whilst still working within the dietary prescription your dietitian has provided for you. This one is a more 'numbers' based mealplanner. Your dietitian will advise you of what is available to use and what they would recommend.

BUILD A KETO MEAL PLANNER

The KDRN are delighted to be launching the first visual ketogenic portion-size guide. It's a resource designed to allow patients and their families to build meals electronically, whilst being able to visualise the amount of each food they are adding to their meal.



When starting Ketogenic Dietary Therapy (KDT), there is a lot of new information to consider, and meal planning for the first time can seem daunting. Most patients or carers at the beginning of their KDT journey are not used to weighing or estimating the weights of different foods. Using this tool within teaching sessions, can help families to plan meals for the first time, whilst being able to see how much of each ingredient they are including.

When planning meals at home, rather than realising mid-way through cooking that an amount of food in a planned recipe is a lot smaller or larger than expected, this programme allows portion sizes to be easily adjusted in advance, before starting cooking.

For some people, the thought of starting a ketogenic diet for themselves or a loved one, can seem particularly overwhelming if they are needing to draw upon numeracy skills they perhaps have not used since their school days.

40% of adults in the UK do not feel confident working with numbers, and for some this may be a barrier to accessing KDT for themselves or their children.

This resource can take the 'maths' out of meal planning, as the macronutrient totals of the combined ingredients are automatically calculated.

We have not included branded products, as individual formulations may change; instead the values displayed are an average of all brands and varieties of the ingredient listed.

Many thanks goes to Matthew's Friends Ketogenic Dietary Therapies Charity for their support, funding and organisation of this project. With thanks also going to VitaFlo for their sponsorship.

We hope you find it a valuable addition to your practice and hope the families you support can find it useful.



Nicole Mills – Paediatric Dietitian

Cambridge University Hospitals NHS Foundation Trust

On behalf of the KDRN (Ketogenic Dietitians Research Network)

KETOGENIC MEALPLANNERS

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.

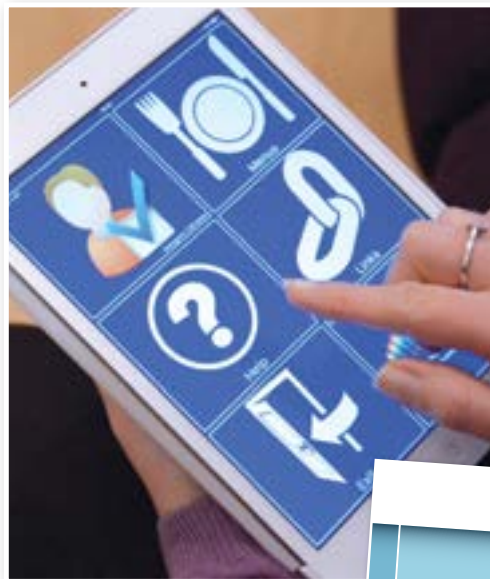
This programme must be used with the close supervision of a ketogenic dietitian and medical supervision. It is available with all foods from "The Composition of Foods" data set (version 7), however any food can be entered directly into the programme thus EKM can be used with a personal selection of foods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



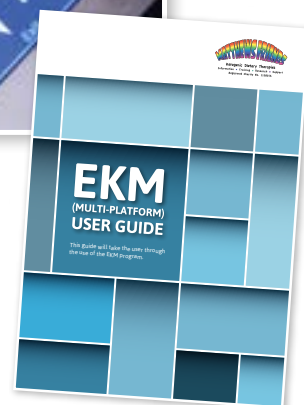
Matthew's Friends are delighted to be supporting the EKM and sponsoring its continuing development so as to benefit not only families but also ketogenic dietitians.

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 Matthew's Friends
#KetoKitchen YouTube channel
 for Ketogenic recipe
 demonstrations and tutorials!

FURTHER INFORMATION AND RECIPES AVAILABLE VISIT:
 🌐 **www.matthewsfriends.org**



Introduction and preparation for Medical Ketogenic Therapies in children

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, especially as we now have registered offices in Canada, The Netherlands, South Africa and New Zealand, all of whom are helping to promote and develop ketogenic services in their own regions.

We invest considerable funds into patient support by providing 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, practical information booklets such as the one you are reading now as well as family and patient events.

We support all the medical ketogenic services in the UK for both adults and children as well as investing in those services by providing funding to expand existing clinics or funding the start up of new or independent ketogenic services. All our information and resources can be freely downloaded from our website or hard copies ordered from our office.

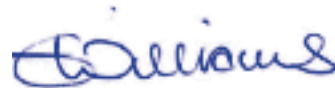
In 2016 we launched our annual KetoCollege training programme for healthcare professionals who want to provide ketogenic therapies for their patients and this has grown each year. We are also a founding Patron of the International Neurological Ketogenic Society (INKS) and Professor Helen Cross OBE continues to lead our very distinguished medical advisory board.

For over 20 years 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.

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



RUNNING THE MATTHEW'S FRIENDS TELEPHONE SUPPORT LINE MEANS I GET TO TALK TO WONDERFUL, BRAVE AND INSPIRING FAMILIES EVERY DAY.

YOUR NOTES....

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Ketogenic Dietary Therapies
Information • Training • Research • Support
Registered Charity No. 1108016

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 **Support-line Number: 0788 4054811**

 **Website: www.matthewsfriends.org**

 **E-mail: enq@matthewsfriends.org**

