SPECIAL FEATURES INSIDE:

• MESSY/SENSORY PLAY - PAGE 6

• NEW KETOSTAR - PAGE 15

• HOLIDAYS & KETO BY EMILY - PAGE 16

AND MUCH MORE!

THE ROLE OF THE KETOGENIC NURSE AND DIETETIC ASSISTANT (DA)

NEW – Find out more about the role of a Ketogenic Dietetic Assistant and Ketogenic Nurse with this free webinar for health professionals available now from KetoCollege. See page 19 for more details.

KETO ON A BUDGET

With Summer holidays looming and everyone feeling the pinch in their purse when food shopping – we’ve got some handy tips and recipes to help ease the strain – see page 8.

The second KetoCollege Advance meeting took place 21-23 May 2024, for health professionals supporting families on medical Ketogenic Therapies.

Look out for the full article in the Autumn issue!

CHECK OUT OUR FABULOUS FUNDRAISERS

Greg, Lewis & Shenise on page 23/24
Matthew’s Friends Supporting Patients and Families

ONLINE INTRODUCTORY & INFORMATION FILMS
At your leisure, view films made by the Matthew’s Friends Team led by the Chair of our medical board, Professor Helen Cross OBE. Topics include:
- History of the diet
- Different types of diet available
- The need for medical management
- Side Effects of the diet
- Recipe and ingredient demonstrations
- Family Stories

FACEBOOK FAMILY SUPPORT FORUM
Once you or your loved one is on a medically supervised ketogenic dietary therapy, you can gain access to our Facebook support forum by filling out the request form and sending it to us. You will then be invited to join the forum and get to know other families in the same situation as yourself, where you can discuss any problems or concerns you may have or share your successes, recipes and handy hints and tips that makes things work for you.

DIETARY THERAPY
This is a safe and confidential forum which is moderated by the Matthew’s Friends team of past and present Ketogenic Ambassadors and Regional Co-ordinators all of whom have a wealth of experience. Our Ketochefs will also be on hand to answer any food questions for you and from time to time we will have guest professionals join us for specific question and answer sessions on topics that YOU want addressed. Click the button below for access to the films and the Facebook support forum.

ALTERNATIVELY YOU CAN USE THE QR CODE

CONTACT US...

NEWSLETTER ARTICLES:
- enq@matthewsfriends.org

FOR RECIPE INFORMATION:
- Kethokitchen@matthewsfriends.org

FOR KETOCOLLEGE INFORMATION:
- info@ketocollege.co.uk

Matthew’s Friends, St. Piers Lane, Lingfield, Surrey, RH7 6PW
01342 836571
www.matthewsfriends.org
www.ketocollege.co.uk

Matthew’s Friends are proud to be founding patrons of the International Neurological Ketogenic Society (INKS) together with our sister organisation in the USA, The Charlie Foundation. This society is bringing Ketogenic experts together from all over the world.

INTERNATIONAL NEUROLOGICAL KETOGENIC SOCIETY
www.neuroketo.org

Adults with drug-resistant epilepsy, who have failed TWO or more medications

CONSIDER A MEDICAL KETOGENIC DIETARY THERAPY

Contact Matthew’s Friends at enq@matthewsfriends.org for an information pack.
www.matthewsfriends.org
Global Nutricia Complex Epilepsy Expert Day
Nutricia Research Centre in Utrecht, the Netherlands

I was lucky enough to attend this meeting at the research centre. This is where the Nutricia products are designed and made. There is a working replica of the small bowel, on which they can test the products, to best learn how each nutrient is broken down and absorbed to provide optimal nutrition!

The day was very full. Dr Anita Devlin, Consultant Paediatric Neurologist, Newcastle’s Great North Children’s Hospital, did an excellent job of chairing the meeting, which started with an overview from Eric Kossoff, Professor of Neurology and Paediatrics at John’s Hopkins University, Baltimore. He gave a whistlestop tour of the past 103 years of Ketogenic Dietary Therapies (KDT). This was followed by Professor Auvin, Epileptologist and Paediatric Neurologist, Robert Debre University Hospital, who covered the wide spectrum of KDT use and its anti-inflammatory effect on the brain.

Professor Anastasia Dressler, Epileptologist and Paediatric Neurologist at The Medical University of Vienna is very passionate about and has done much research with babies and infants on KDT. She shared her experience and knowledge of working with this specific age group. The need to target these children, to try KDT early and potentially prevent the epilepsy and intractable seizures from becoming established, interrupting development and learning, and ultimately making the epilepsy more difficult to treat in the future.

Dr Elles Van Der Louw, Ketogenic dietitian at the Erasmus MC Sophia children’s Hospital in Rotterdam, did an amazing job of covering the practicalities of initiation, management and weaning KDT in 45 minutes!

Monitoring was an interesting topic, most centres seemed to use blood monitoring, some urine testing. Professor Auvin advised that his centre only test their patients’ level of ketosis at hospital appointments. If they show signs of excess ketosis or illness, the patients are advised to come into hospital to be reviewed!

I suppose this is much like the days pre blood monitoring, where urine monitoring only really let us know if our children were in ketosis, but it did not give particularly accurate levels, so we had to go by symptoms. Then we were given protocols to treat the symptoms at home. If the treatment needed repeating after 30 minutes we needed to seek medical attention.

I wonder how the families feel. Although I didn’t overuse our blood monitor in the last couple of years that Greg was on KDT, I always felt better knowing that I could test if he wasn’t quite right one way or another. It is certainly easier for clinicians I think, especially initially to have ketone testing as part of their monitoring tool kit to assist in finetuning the diet.

It may also be particularly important for young children to be monitored more closely as they can be prone to excess ketosis and low blood glucose. There is much discussion regarding the relevance of ketone levels in controlling seizures, and yet for some it does seem important. As always, it is individual!

The last presentation I attended by Dr Frank Brandhoff, Epileptologist from Germany’s Epilepsy centre in Kleinwachau, was focused on adults on KDT.

The centre takes adult patients on a residential basis for assessment for up to 3 weeks. KDT is one option to try. They have cooking facilities on site, so that all training may be given.

Over 6 years Dr Brandhoff has seen the good effect of KDT in adults. He also see’s the differences for those adults who are living independently and the impact that KDT has on their social wellbeing, the emphasis being on them managing the diet for themselves, which may be empowering, but also difficult to maintain, with so much of life/socialising revolving around food!

Dr Brandhoff presented a couple of GLUT 1 DS patient case studies. Both showed that improvements in both seizures and movement disorder were possible at any age.

Throughout the day Chef Derek kept all the delegates topped up with his delicious Keto snacks and they were certainly needed because it was a busy day for all.

There was a lot of interest in the MF table/resources and my best part of the day was meeting some of the scientists behind the Nutricia products we use to make KDT a little easier for families. I was able to give them some insight into just how much difference their products can make to people’s lives by telling them all about my son Greg and how KDT turned his life around and sorry, but despite all their amazing science, he drank his Liquigen mixed with diet coke!
Young Epilepsy (YE) Webinar

Ketogenic Dietary Therapy (KDT) in infants

Matthew’s Friends was invited by Young Epilepsy, to take part in a webinar looking at the use of KDT in infants.

The webinar was chaired by Professor Helen Cross. She started by explaining the history and basics of KDT, with a general overview of the latest research. Research highlighted the need for a randomised controlled trial to find out if KDT would be safe and effective in infants.

The Ketogenic Diet in Infants with Epilepsy (KIWE) trial aimed to find out.

Dr Natasha Schoeler, Senior Research Fellow and Specialist Paediatric Dietitian, GOSH, presented the findings of the trial.

KIWE Trial

Infants from 19 different sites in the UK were involved. Half were randomised to start a new anti-seizure medication (ASM), the other half to start KDT. The new treatment was added to any ASM’s already being taken. 2/3rds of the infants had been diagnosed with a syndrome, most commonly Infantile Spasms.

In terms of seizure freedom both treatments were judged to be equally effective, with approximately 12% of infants becoming seizure free. However, the need for changes in treatment required in the infants, in the ASM arm during the first 8 weeks (usually increasing dosage) was 44% whereas in the KDT arm only 14% needed changes in their current ASM’s. This was significant when you think of the instability any medication changes can bring and the effect that it has on quality of life. This was reflected in the quality-of-life feedback at 8 weeks, things like overall behaviour and overall health were reported as more favourable in those on KDT. KDT is generally viewed as a time-consuming treatment when compared with giving a medication. Surprisingly parental time management in the KIWE study was reported as equal in both groups.

Parent Experience

A keto Mum Rai, then shared her experience of following KDT with her daughter as part of the KIWE trial.

Rai’s journey prior to finding the trial was as you can imagine, a rollercoaster! Once on trial it took a few months to find stability. Struggling with constipation and reflux. She had great support from the GOSH team, and that helped Rai and her family to stick with it. All the hard work paid off, with her daughter becoming seizure free and starting to meet those all-important milestones!

The Implications for services and resources

Our CEO Julie Fountain acknowledged the devastating effects of uncontrolled seizures; interrupting development and learning and ultimately making the epilepsy more difficult to treat in the future.

Although families are already bewildered and scared, coping with an epilepsy diagnosis, she proposed that infancy may be the best time to practically implement Keto, with formula initially being the main source of nutrition and tastes/preferences not yet established. Ketogenic formula is available for bottle feeding and there is ongoing work and research to further support combining breast-feeding with Keto – an important consideration for many parents.

Choices and control are also less of an issue in infancy. When weaning onto solids, this could be straight on to keto friendly foods, such as cheesy celeriac mash, avocado and other tasty foods.

The Future Challenges raised by Julie

- Those early months of life pass by very quickly. Perhaps KDT may be considered earlier than it presently is? – currently after 2 ASM’S have been tried, we know that multiple medications are often failed before Keto is considered.

- What are the potential long-term effects of starting KDT specifically in infancy, i.e. on growth?

- Will infants need to stay on KDT for the usual recommended 2 years or if the diet is effective could this be reviewed and perhaps weaned off earlier?

- Whilst there are some very effective KDT nutritional products available on prescription very few are available for use in babies. Most are only suitable for over 3-year-olds.

- Where infants are prioritised to start KDT. What will the impact be on waiting times for older children? As we know, in some areas waiting lists can already be lengthy. An increase in services will undoubtedly be necessary, as will more specialised dietitians to work in this area.

Looking to the future Matthew’s Friends will continue to support KDT services and families with information and resources. We plan to follow up with the practicalities of KDT in infants in our Autumn newsletter.

The webinar can be viewed here, on Young Epilepsy’s YouTube channel.

VIEW WEBINAR HERE
DON’T FORGET TO JOIN OUR PRIVATE FORUM

CLICK HERE TO JOIN

OPEN TO PATIENTS/PARENTS/FAMILY MEMBERS WHO ARE ON A MEDICALLY-MANAGED KETOGENIC THERAPY.

Live chats alternate Monday/Tuesday night 8 – 10 PM.

Take the opportunity to come and ask your keto questions, share any difficulties, and support each other on your keto journey.

Don’t miss interacting with our guest speakers! Post any questions you may have for them on the forum.

<table>
<thead>
<tr>
<th>Date</th>
<th>Speaker/Topic</th>
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<tbody>
<tr>
<td>July (Date to be confirmed)</td>
<td>Nicole Mills RD Cambridge on MCT</td>
</tr>
<tr>
<td>August</td>
<td>Holiday time - No Speakers – Usual chat nights</td>
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<tr>
<td>TBC</td>
<td>Chef Neil on Budget Keto tips</td>
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<tr>
<td>TBC</td>
<td>Emma Cameron RD – Weaning Ketogenic Diet</td>
</tr>
<tr>
<td>TBC</td>
<td>Genetic Testing – Speaker TBC</td>
</tr>
<tr>
<td>8th October 2024</td>
<td>Lisa O’Brien ESN– Weaning medications</td>
</tr>
</tbody>
</table>

WE WILL ALWAYS RECORD PRESENTATIONS WHERE SPEAKERS ARE AMENABLE, TO POST ON THE FORUM FOR THOSE UNABLE TO ATTEND ON THE NIGHT.

Zoe Simpson RD, Great Ormond Street Hospital, gave a very in-depth presentation on monitoring of KDT. It got some great discussion going.

Zoe responded to questions from forum members and stayed on for a general discussion following her presentation. The recording of this session along with all previous and more recent recordings can be viewed in the forum, for members only.

Please email: val@matthewsfriends.org if there are any particular subjects you would like covered!
MESSY/SENSORY PLAY WHILE FOLLOWING A KETOGENIC DIET

Messy or sensory play can be about exploring how things feel, smell and taste. Many messy play ideas involve food - some of which are rich in carbohydrate.

This means that some traditional messy play ideas may not be suitable for a child following a ketogenic diet - particularly if they enjoy exploring with their taste!

The KDRN have a great guide to help! This resource was created by the Ketogenic Dietitians at The Royal Manchester Children’s Hospital with the help of Matthew’s Friends – check it out via this link or search online ‘KDRN messy play’.

SURVEYS, POLLS & FOCUS GROUPS

We have had a flurry of activity recently in this area!

Where you receive a request from us to respond to a survey or poll, or perhaps take part in a focus group - rest assured that Matthew’s Friends only collaborate with trusted organisations who are focussed on benefitting the families and parents that we support and the families that we know are coming in the future. Most recently these have been on behalf of GOSH-ICH, KDRN (Ketogenic Dietitians Research Network), CORE-KDT/University of Plymouth and relevant medical nutrition companies. We really appreciate the responses given and the time taken to help make a difference, thank you!

If you would like to be part of a Matthew’s Friends’ Focus Group of parents/carers of children on a Ketogenic Diet or adult patients on diet, please do get in touch, we’d love to hear from you!

Please email: julie@matthewsfriends.org
HOPE for Paediatric Epilepsy: London, is a registered national charity that provides support and respite to families with children affected by epilepsy.

One of their initiatives is donating anti-suffocation pillows to children who have convulsive seizures in their sleep. These pillows contain air holes that allow a child to keep breathing if they are facedown while having a seizure, which could potentially prevent or reduce the chances of SUDEP.

HOPE provide these pillows free of charge to any child in the UK who has seizures in their sleep and who also has a clinical letter to confirm this.

Please see the details below:
- One pillow can be claimed for each child.
- The child must have had seizures in the last year to qualify.
- There has to have been at least 1 seizure at night in the history of the child’s epilepsy.
- The child must be between the ages of 2 and 18 years old.

If your child fits the above criteria, please email the HOPE Team with a copy of your child’s clinic letter to claim a free pillow: info@hopeforepilepsylondon.org.uk

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**UPDATED RESOURCES**

Our Food Choices and Colour & Shine booklets have both been refreshed and updated (September 2023).

Food Choices is a useful resource for all patients on a Ketogenic Diet, with comprehensive information on food labelling and food choice lists for carbohydrates, protein and fats.

Colour & Shine is aimed at older children and adults – a fantastic resource packed with useful information and recipes. Colour & Shine is only available via your dietitian or on request from your ketogenic dietitian.

Both resources are available in hard-copy (UK only) and digital formats.

Email: resources@matthewsfriends.org

All our printed materials are available free of charge.

CLICK HERE TO DONATE TO MATTHEW’S FRIENDS IN SUPPORT OF THESE AND FUTURE MATERIALS 🅱️
Following a ketogenic diet therapy (KDT) is seen as a costly way to eat. Despite losing the carbohydrate (CHO) loaded foods, they are generally cheaper than the fats that we replace them with! There are also now many special tasty products like the low CHO breads, that have made KDT easier, by giving us products that do not have to be made from scratch and look the same as ‘normal’ bread etc. The trouble is, they can be expensive!

SOME WAYS TO KEEP COSTS DOWN

Organisation, knowing what you are going to make and then making a shopping list so that you stick to buying what you need rather than, what I know I do, go in for a couple of things and come out with 10 things I didn’t need, usually forgetting what I went in for in the first place. There is so much to choose from in the supermarkets, that it makes it so easy to do! Although I would not be keen to go back to the days of no fridge and shopping for dinner daily, it must have cut down on wasted food!

On keto we have the added reality that because the foods we use are often those that need refrigeration like cream, low CHO milks and yoghurt, baked goods have no sugar to preserve them so also need to go in the fridge. Thank goodness for freezers!

Freezers are a great way to reduce wasted fruit and vegetables. Buying frozen veg and berries or maybe growing your own and freezing it. Even better get friends or relatives to grow them specially for you?! Things like rhubarb grow well, low CHO, great fibre! My neighbour grows salad leaves in a tub, and they seem to just keep growing!

Freeze things like the online products also means that you can take out what you need as a treat on the weekend or on special occasions.

Most supermarkets have loyalty cards which can help with saving the pennies.

<table>
<thead>
<tr>
<th>TESCO CLUBCARD</th>
<th>NECTAR CARD</th>
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<tr>
<td>LIDL PLUS</td>
<td>ASDA REWARDS</td>
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<tr>
<td>MY WAITROSE</td>
<td>MORRISONS MORE</td>
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<tr>
<td>M&amp;S SPARKS</td>
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One of Mo’s great tips is to bulk buy baking goods like ground almonds. Alongside that it’s good to then batch up things like rolls/muffins/biscuits and freeze them. Ground almonds have a pretty good shelf life but just be careful with flax as it needs to go in the fridge once open and then has a use by date, the Linwoods brand I have is 45 days from opening. Nuts and seeds are very unpleasant when they turn rancid!

Maybe worth joining Costco or maybe you have friends or family who are members? You can buy 5L tubs of Hellmann’s mayonnaise (lasts 3 months in the fridge once opened). Big slabs of butter etc, much cheaper, Greg also gets his diet Pepsi by the slab from Costco.

Eating out can be expensive, hopefully we will have some good weather over the summer to get out and picnic. Or on rainy days I remember having picnics indoors! It’s worth investing in some ice lolly moulds for the summer too. They are very cheap and can be made with any own brand sugar free squash or fizz. You could also make some milk lollies, using the Alpro light milks.
**PRESCRIPTION PRODUCTS**

We are lucky to have a range of prescription products that can really cut down on shopping bills.

Nutricia provide their range of powder and liquid Ketocal products that may be used as complete feeds, supplemental shakes or added to recipes to increase fat content. They also have MCT oil and Liquigen (MCT emulsion) available.

Vitamin supplements are available, Phlexyvits, in tablet and powder form. Chef Derek is always happy to showcase how to incorporate these products into meals!

Vitaflor provide their range of products, including K.Flo, K.Quik, K.Yo puddings and MCTprocal, all high in fat. They also supply vitamin supplements - FruitiVits.

Chef Neil is a whizz at whipping up great low-budget keto meals!

The KetoCare range are I know used by many. Porridge, muesli, biscuits, bars with recipes and even a couple of ready meals are available.

We also have Cambrooke who provide their meal replacement shakes and flour substitute, KetoVie Café Kwik Mix with a recipe book.

Kanso products on prescription in UK are presently limited to their DeliMCT Cacao Bar and MCT oil.

Ask your dietitian about which prescription products may be suitable for you - they can also arrange for taster samples to be sent to you!

**BOOKS**

As always, be careful if you are buying books online, they are not aimed at medical keto! The good ones are great for inspiration, the worst claim to be keto but are not even very low CHO! Not great wasting money on books that are not what they appear to be!

If you are lucky enough to have a local library, they may have some low CHO recipes books, or they may be happy to get some in?

There is a similar problem with buying ‘Keto’ labelled food. It looks amazing and is often expensive. My advice is if it looks too good to be true it probably is! Check the macronutrients (carbohydrate, protein, and fat amounts) and look at the ingredients! If you are unsure, check with your keto team before buying. Again, not great wasting money on food that is not what it appears to be!

**FOOD LABELLING GUIDANCE**

<table>
<thead>
<tr>
<th>UK/Europe/Australia</th>
<th>USA</th>
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</thead>
<tbody>
<tr>
<td>All products labelled per 100g</td>
<td>Products labelled per portion size</td>
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</tbody>
</table>

**Example**
- Label per 100g contains 50g CHO
- 100 divided by 50 = 2
- 2g product = 1g CHO

<table>
<thead>
<tr>
<th>USA</th>
<th>UK/Europe/Australia - fibre</th>
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<tbody>
<tr>
<td>Fibre is included in the total CHO. Fibre is not absorbed &amp; therefore will need to be subtracted from the total CHO amount.</td>
<td>Always use figure for total carbohydrate. Fibre has already been taken off.</td>
</tr>
</tbody>
</table>

Net carbohydrate is the amount of carbohydrate once fibre has been removed.
ARE YOU ELIGIBLE TO CLAIM BENEFITS?

There is excellent guidance re the benefits that may be available to people with epilepsy at The Epilepsy Space (Epilepsy Action) and The Epilepsy Society. You can visit online (see below) These benefits can really make a difference!

Filling in benefit forms is always, as far as I have experienced, an absolute nightmare! We want to celebrate the good things and achievements that are made by our loved ones, not dwell on what they can’t do or need help with! The problem is also that the life we live is ‘normal’ to us, so we tend to forget to include everything we should.

It can make following Ketogenic Dietary treatment (KDT) feel negative too, because you must consider all that it involves daily, and how long it takes. Giving a tablet in terms of the time it takes is certainly shorter and easier! We know that following KDT is far more time consuming, but we wouldn’t be doing it if the medications had been effective. Remember that when you use KDT as your treatment, you are doing it, a big responsibility, but when it works, so empowering. Of course, your Keto team and charities like ours will support and help you on your keto journey but at home you are doing all the hard work, and everything takes time.

Specific Keto related things you may include or think about when filling in the forms:

ABOUT LEARNING AND SHARING INFORMATION

- You are having to learn a new skill, include training time, it’s not just the initial training, it’s ongoing learning too.
- Learning the basic principles of KDT and how it is implemented.
- How to make up meals, how to batch up meals.
- Changes to Plastics - Mixed feeds hanging time, infection control, possible changes to giving feeds i.e. perhaps changing to bolus feeds. Storage.
- How to monitor, learning how to check blood ketones/glucose and check urine. record and report responses.
- Learn what to look out for/side effects.
- How to adapt in different scenario’s, during illness, going out, hospital visits planned or emergency, different activity levels, going on holiday, during puberty/ menopause at school/respite/work, special occasions, and cultural celebrations.
- You don’t learn this all-in-one go. Over time you become an expert on what works best for you. You can then, explain, pass on information to family, friends and anybody else who may be involved in your/your loved one’s care, to maintain the diet in all situations and avoid mistakes. KDT should be considered an Anti-seizure medication.
- That very much includes doctors/nurses/dietitians/ pharmacists and other health workers outside of our ‘Keto’ world! An example – liaising with your local pharmacist to ensure medications are carbohydrate (CHO) free. Sourcing CHO free medication during common illness.
ABOUT THE MONITORING

• Checking blood ketone/glucose levels (and knowing how to recognise and treat excess ketones/hypoglycaemia).
• Tracking the number of seizures and observing for changes in severity and recovery.
• Monitoring symptoms beyond seizures, to evaluate treatment effects e.g. levels of dribbling, behaviour, sleep, alertness, appetite etc. Have others noticed changes?
• Monitoring general impact on quality of daily life.
• Checking weight/height and monitoring growth changes e.g. puberty.
• Tracking activity levels.
• Monitoring for side effects and taking positive action:
  - Constipation – Sourcing high fibre foods, encouraging fluids, activity, massage.
  - Kidney stones – observing urine for blood/gravel, encouraging fluids.
  - Bone health, regular blood/urine tests. Exercise, ensuring regular vitamin/mineral supplements are taken.
  - Reflux, positioning at mealtimes, small frequent fluids.
• Liaising with your Keto team via regular phone contact and sending in tracking forms and other documentation via email etc.
• Hospital appointments
• Preparation for regular blood tests

These points will not all be appropriate to everyone on Keto, some are very hard to quantify in terms of time spent and will change as you become your own or your loved one’s keto expert.

It may be easiest to jot down times as you go, (when you think of it) i.e. for a meal batching session or filling in and sending a week of monitoring to your team. You could list tasks and add to the forms if easier. Or average out times. The more information you collect as you go, the easier it makes the forms to fill in! They are something extra for families already struggling to make time for everything else but will help in the long run to reduce financial pressures!

ABOUT THE FOOD

• Cooking from scratch – weighing every ingredient of every meal, sourcing special ingredients and finding bulk buy cheaper ingredients - it’s not always straight off the supermarket shelf!
  • Sourcing recipes online
  • Time batching, storing, planning meals.
  • Time spent testing recipes.
  • Sourcing equipment that lasts. Scales/ muffin trays/ Non leak pots.
  • Prescription products – liaising with product companies for deliveries or via GP.
  • Learning how to use a computer program/time spent making up recipes.
  • Feeding time, ensuring all is eaten and in balance.
  • Fluids ensuring adequate intake.
  • Vitamins (essential) Time disguising/taking?

LINK FOR HELP IN FILLING OUT THE FORMS
BUDGET RECIPES

FROM OUR KETOKITCHEN

Mo has been busy in the keto-kitchen, creating some delicious dishes to complement our ‘Keto on a Budget’ article in this issue.

CELERIAC GRATIN

INGREDIENTS
- 120g Celeriac - boiled
- 60g Double cream
- 15g Mature cheddar cheese
- You will also need some seasoning

METHOD
- Pre heat the air fryer to 180c or Pre heat conventional oven to 180c / fan 160c/gas 5.
- Grate the cheese.
- Cut the cooked celeriac into thin slices.
- Layer the celeriac into a small ovenproof dish with a little seasoning.
- Pour over the cream and top with the grated cheese.
- Cook in the air fryer / oven until heated through and golden brown.
- Mine took 12 minutes in my air fryer.

CLASSICAL 4.00:1 RATIO
CHO: 3.25G  FAT: 36.13G
PROTEIN: 5.79G  KCAL: 361

MO’S TIP
Do not overcook the celeriac when boiling, you don’t want it too mushy. This makes a nice lunch or supper but can be used as a side dish. It goes well with fish, sausages, ham or other vegetables. Good for BBQ time, it goes well with a burger or sausages.

CELERIAC AND LEEK SOUP

INGREDIENTS
- 120g Celeriac
- 20g Leeks
- 25g Butter
- You will also need a KNORR stock cube dissolved in ½ pint of hot water and ½ teaspoon of mixed dried herbs.

METHOD
- Peel the celeriac then weigh it, cut into small pieces.
- Slice the leeks.
- Melt the butter in a saucepan and gently sauté the vegetables for 2 minutes, add the stock and herbs.
- Simmer until the celeriac is soft then turn off the heat.
- Blend until smooth.

CLASSICAL 3.91:1 RATIO
CHO: 3.49G  FAT: 21.13G
PROTEIN: 1.91G  KCAL: 212

MO’S TIP
This is an economical soup and is easy to batch up. If you need to get more fat in, then a little cream goes well in this soup. I used a chicken Knorr stock cube as I find it has a lot of flavour, but you could use a vegetable one if preferred. You do not need to add salt to this recipe, but a little black pepper is OK.
**CHEESE AND CELERY COLESLAW**

**INGREDIENTS**
- 40g White cabbage
- 20g Carrots
- 20g Mature cheddar cheese
- 35g Mayonnaise – HELLMANN’S
- 15g Celery

**CLASSICAL 3.51:1 RATIO**
CHO: 3.80G  
FAT: 34.80G  
PROTEIN: 6.13G  
KCAL: 353

**MO’S TIP**
This travels well in a plastic pot. Will keep for a few days in the fridge. This is an economical meal. Good for BBQ time, it goes well with a burger or sausages.

**METHOD**
- Finely slice the cabbage.
- Chop the celery.
- Season with a little salt or onion salt & black pepper.
- Add the mayonnaise.

**SPINACH TORTILLA WRAP**

**INGREDIENTS**
- 25g Spinach
- 40g Eggs
- 10g Vegetable oil

**MKD 0.05G CHO TOTAL**
CHO: 0.05G  
FAT: 13.74G  
PROTEIN: 5.69G  
KCAL: 147

**MO’S TIP**
This is virtually carb free.

**METHOD**
- Remove the stalks from the spinach then weight it.
- Chop the spinach as finely as you can, a blender helps a lot.
- Whisk the egg with a pinch of salt, then beat in the chopped spinach.
- Heat the oil in a small frying pan on a medium heat, pour in the spinach mixture and spread as evenly as possible, cook until the top starts to look dry, then flip it over and cook on the other side.
- Turn out then add a filling of your choice to suit the ratio.

**PLEASE ENSURE YOU CHECK PRODUCT LABELS FOR VALUES**
These recipes will need to be adapted to EACH INDIVIDUAL’S prescription. Please take these recipes to your dietitian and he / she will help you to do this.

**PLEASE DO NOT ATTEMPT ANY TYPE OF KETOGENIC DIET WITHOUT MEDICAL SUPERVISION**

**VISIT MATTHEW’S FRIENDS**

#KetoKitchen YouTube channel  
FOR KETOGENIC RECIPE DEMONSTRATIONS AND TUTORIALS!
MO’S TIPS:
HOW TO BE AS ECONOMICAL AS YOU CAN IN PREPARING KETO MEALS

• Keep meals simple whenever possible with minimal ingredients.

• Organise your ingredients. You need to know what you have in, what needs using up or you can end up wasting food or buying things you don’t need.

• Tried & tested recipes help with wastage – Knowing exactly the ingredients you need, will mean less of buying things you don’t need.

• Economise by using supermarket own brands - Using supermarket own brands will help save money, especially with foods like butter, cream and eggs. Using their economy range does not mean poor quality!

• Eggs are a cheap way of getting protein into a meal. Spanish scramble, Frittata and bacon & eggs are quick economic meals. Recipes are available if you don’t already have one.

• Buy wonky vegetables and fruit. They offer a great saving and are perfectly ok. Wonky vegetables make great soups.

• Mushrooms and tinned tomatoes make great soup.

• Most supermarkets offer economy fruit including some berries.

• Make your own low carb bread. This can be batched and frozen. Branded low carb bread is expensive. See our recipe for bread rolls online. They are so quick to make and freeze well.

• Have a supply of muffins sweet and savoury in the freezer. They are great for packed lunches and when you are travelling. Coconut is cheaper than ground almonds. I find buying ground almonds in 1kg bags the best value. in fact, this will apply to a lot of store cupboard ingredients. The bigger the pack the better the value.

• Meat is quite expensive now, but chicken offers the best value along with mince. I am a fan of lamb mince. It makes great meatballs and burgers and it’s very tasty.

• Using our ovens these days is also costly so organise a cooking day to make full use of the oven. If you can invest in an air fryer, this will prove useful in saving the electricity as well. There are air fryers available now that are like small ovens. I have one that bakes pies cakes and even Yorkshire puddings! Much better than heating a full-size oven.

I have added a few recipes for the article. You will find lots more on our Keto Kitchen website.

The best advice I can offer is to be economical with stress. You are doing what you do every day anyway... cooking! Weigh your ingredients correctly and follow either your own or someone else’s recipes then very little can go wrong.
Now, we’ve never had a KetoStar nomination for a pet before, so we were delighted when Catherine Lawson sent in a nomination for their border collie, Buzz who is a constant companion for daughter, Ava.

Please read below Catherine’s nomination for Buzz, we are sure you will all agree, he really is a wonder-dog! They do an amazing job in supporting adults with drug-resistant epilepsy with medical ketogenic diets and raising awareness! THANK YOU! If you know of anyone you think deserves the recognition of a KetoStar Award please do let us know by nominating them using our form.

‘Buzz is our Border Collie but most importantly he is Ava’s furry brother. From the moment Buzz met Ava, when he was 3 weeks old, it became clear they would have a special bond. They are play mates, best friends and if Ava becomes unwell, he is beside her, alerting us and reassuring her as she recovers.

Buzz is not a trained assistance dog but in terms of Ava’s seizures or Glut 1 episodes, he just knows, and he is there for her. If we need to call for an ambulance he goes into his den when the paramedics arrive to keep out of their way, but he is always ready with cuddles when they have finished (cuddles for paramedics as well as Ava obviously).

When Ava is struggling with her speech, she always knows Buzz will be patient and listen. When she is sad, he makes her happy, when she is cross, he lets her tell him why, when she is bursting with energy, he is ready to play. It is impossible to put into words how very special he is, Buzz is the best! He is our family’s Keto Star.’

Thank you so much for introducing us to Buzz, what an amazing dog he is. Buzz, shown below with Ava, certainly is deserving of his KetoStar certificate and special rosette!

CONGRATULATIONS BUZZ!
Spring has sprung so our thoughts have begun to turn towards the summer picnics and beach visits, the holidays abroad and increased excitement. I’m sure for many, us included, this period of time brings some concerns.

How to overcome the request for ice cream like peers, navigate extra baggage and food for the planes and travel friendly picnics for sandy days at the beach!

I thought I could share what we do as a family when navigating this time of year to hopefully help others and maybe provide some inspiration!

**Beach Days**

Beach days are a favourite here! Whilst Ella has a gastronomy button, we avoid using it on beach days and she instead opts for a K-Yo and some berries for the day. We have also previously taken picnics (see our lunch post blog Ella’s Keto blog - Matthews Friends for some ideas!) so she matches everyone else and again avoids the use of her button as sand + syringes are not a great match and when she is on the beach, she does not want to leave it so no opportunity to pop to the beach cafés!

We take a sugar free lolly with us too for an alternative to an ice cream. Discussing the treat before leaving helps manage expectations for us!

**Ice-cream alternatives and at home treats**

Our favourite ice-cream recipe uses a base of mascarpone and double cream and we add in blended fruit or dark chocolate chips depending on what Ella fancies. It really is the easiest treat!

**Strawberry Icecream**

- 20g strawberries, pureed
- 16g mascarpone
- 10ml double cream
- Liquid sweetener to taste

Pop strawberries into bowl and cover and sprinkle with some powdered sweetener before leaving to rest for an hour or so. Once rested, blitz the berries into a puree.

Mix the cream and mascarpone together and once combined, mix in the strawberry puree. Add sweetener to taste, if desired.

Pop into the freezer for a couple of hours before serving. If freezing multiple portions, remove from the freezer a few minutes before serving to allow it to soften slightly.

**Macros for my ingredients**

(cream macros may vary):

- **Fat:** 10.49g
- **Protein:** 1.23g
- **Carbohydrates:** 2.28g
- **Calories:** 108
- **Ratio:** 2.99:1

We serve with a normal ice cream cone for some normalcy which she adores.

There are a few shop purchased ice lollies she enjoys too which are offered alongside a Ketocal milkshake to balance her macros. Judes ice creams are our favourite brand and are definitely available in more places now and are well worth a try this summer!
Flight checklist

Flying is something that can feel very intimidating when managing a strict diet. We have travelled quite a few times now and therefore have it down to a fine art!

Firstly, you need to arrange special assistance and request an additional bag. They will want a weight so find yourself a carry on case with wheels and add the supplies you’d need to take before calling so you can provide an estimate.

Next, you’ll need to call your dietitian who will write a letter detailing all the items you need to take on the flight with you. Ask them to include diluted squash so you can keep that fluid with you throughout security too!

When packing the bag, make sure the liquids are accessible as they will all need to be tested, so also ensure you give yourselves enough time for the process. The dietitians letter needs to be with the medical food so they can see items are approved. If you can also translate the letter to the language of your destination, it will make the return flight easier!

All-inclusive holidays

When we travel, we travel all-inclusive as holidays are a break for me even if not for the rest of the family and I want access to unlimited cocktails and treats! Yes, we pay for an all-inclusive ticket for Ella too, which is somewhat costly for the amount of food she eats but I’m all for ease on holiday and this works best for us.

I always take my mini scales with me and a list which confirms how much fruit and veg Ella can have for 2g carbs (which your dietitian can provide you with) and she will choose from what’s available to have alongside chocolate puddings or milkshakes. Many restaurants will also share with you the labels for the cheese and meats that they have available for you to grab some snacks but for ease, we stick only to non-processed meats where the macronutrients are stable, such as chicken and fish sources. Mini scales and your macro lists are all you need to make this easier!

For treats, whilst other children are munching ice creams, Ella has a choice of keto treats from cakes (Deliciously Guilt Free) to homemade chocolates (our lunch ideas blog has the recipe) to choose from and the choice is what helps her to feel included and enjoy her holiday as much as all the other children!

Find out more about Ella’s Keto journey here on Matthew’s Friends YouTube channel.

The Winner Bakes It All

Elodie has big dreams for her little cake shop, so when a perfect bigger unit becomes vacant, she’s excited to finally expand. Except it turns out the space has already been snatched up – and by a fitness-obsessed gym bro who hates carbs and sugar!

But when a local influencer offers her the opportunity to bake for a big celebrity wedding, Elodie can’t believe her luck. Until she finds out that her new carb-hating nemesis, Mal, has been hired to cater the same event.

The two rivals have to put their personal feelings aside to work together to pull off the wedding of the year – and they only have two months to do it! But will they be able to resist trying to kill each other, or will sparks – and cupcakes – fly in the heat of the moment?

Review by Val Aldridge

Ha ha, I really enjoyed the job of reviewing this book! Thank you, Jeev!

This romcom is written by a keto mum! I thought it was magic! It made me feel like I was on holiday, such a ‘feel good’ book! Just what we all need when life can often feel like/a constant battle!

The fact that Jeev managed to incorporate keto for epilepsy and for lifestyles in a very factual, pragmatic way was genius! It will be so inspiring for keto families to read but it will also be very informative to those who have no knowledge/understanding of keto, likely without them even realising.

It would make a great British rom com film! Any UK versions of Jim Abrahams to produce it out there please?

The book comes out in paperback (and Kindle) on the 6th of June. The audiobook should come out soon after.
Matthew’s Friends hosted a free webinar at the end of February for all professionals involved in implementing Ketogenic Dietary Therapy (KDT).

Dietetic services are stretched everywhere in the keto world. Our aim was to highlight the roles that nurses and DA’s play for those lucky enough to have them within their keto team.

Zoe Simpson, RD, Great Ormond Street Hospital, chaired the webinar and started with an overview of KDT.

The role of DA’s was split between three Keto teams.

Part 1 was covered by Vicki Whiteley, RD and Richard Hallam DA from Manchester Children’s Hospital.

**PRE KETOGENIC DIET START AND ADMINISTRATION**
- Administration, sending out initial forms, appointments, food diaries.
- Homeward/Vitaflo to you, setting up, change of reg, discontinuation of service.
- Product information/ordering/monitoring.
- Pre-diet lowering carbohydrate - introducing new foods.
- Lifestyle changes.
- Organising of blood/urine testing, collecting & monitoring.
- Telephone contact – reminders, appointment support.
- Support during face-to-face appointments.

Part 2 was covered by Sara Viadero – Prieto DA from Great Ormond Street Hospital.

**ALL ABOUT THE FOOD/COOKING**
- Food labels.
- How to make up a meal using choice lists.
- All in one meals/emergency shake/soup.
- Batch cooking.
- Meal planners/available resources links.
- Keto friendly Sweeteners.
- Keto friendly thickeners.
- Admissions: Planned admissions, Emergency admissions.

Part 3 was covered by Astrid Allford RD and Pooja Gumber DA, from Birmingham Children’s Hospital.

**LIVING WITH KDT**
- Longer term Telephone contact – reminders, appointment support.
- Holidays/travel.
- Eating out/special occasions.
- Useful resources books/websites/forums/chats, support for families.
- Setting up cooking/meet up days for families.

Between the three centres they certainly did a great job of highlighting the huge role that DA’s can play in supporting both dietitian’s and families! They also highlighted the differences in the role of DA from one centre to another.

**AN INTERNATIONAL NURSE PERSPECTIVE**

The role of a nurse in the keto team was presented by Brialie Forster BN, MN, Austin Health, Melbourne, Australia. Of course, not all keto services have a dedicated nurse. Brialie’s presentation will certainly make all services wish they did!

She takes on the role of linking the team together. Below are some of the topics she covered.
- Blood/urine testing, collecting & monitoring, relevance, treatment of hypo glycaemia/hyperketosis.
- Height and weight recording. How/when to weigh.
- Side effects and testing alongside, treatments, constipation, reflux, bone health and growth, Recognising red flags.
- General Illness on keto.
- Keto friendly medications.
- Hospital admission guidance.
- Biochemistry pre and during KD T.

It is amazing to see how the roles overlap, and it really emphasised the benefits of a team approach wherever possible. Using the skills of the professionals where needed, alongside the dedicated support of the DA’s will we hope, enable access for more patients in a cost-effective way, to try KDT in the future.

The webinar is free and available to associated health professionals.
ITALY’S FIRST NATIONAL SYMPOSIUM ON KETOGENIC DIETS

On March 23, 2024, Italy’s first National Symposium on Ketogenic Diets was hosted by Professor Veggiotti in Bologna.

Chaired by Professor Veggiotti from the University of Milan and Professor Antonio Paoli, University of Padua, the symposium convened renowned international experts to discuss the latest discoveries and practical applications of ketogenic diets in treating various neurological conditions.

Professors Joerg Klepper & Eric Kossoff (both Matthew’s Friends’ International Medical Advisors) featured among the international expert speakers and our CEO Julie Fountain presented via video link on the work of Matthew’s Friends.

An exciting addition to the Ketogenic educational calendar for both families and professionals and one that we hope will become a regular event!
KETOGENIC DIET MADE EASY

This information is intended for patients and carers of patients who have been prescribed KetoCal by a Healthcare Professional.

All products shown are Foods for Special Medical Purposes for the dietary management of drug resistant epilepsy, or other conditions where the use of the ketogenic diet is indicated, and must be used under medical supervision.

EVA
Following a ketogenic diet for 6 years

WEANED off all anti-epileptic drugs

3 HOLIDAYS not possible before the diet

LEARNED to swim and ride a tricycle

LOVES school and lives life to the fullest

NO hospital admissions since

HOLIDAYS not possible before the diet
There are so many ways to make your keto moments, with Vitaflo...

Our range of ketogenic products are suitable from 3 years of age onwards and are created for life on the go.

Vitaflo’s Connected Care App helps you and your HCP manage and monitor key aspects of your ketogenic diet. Scan the QR code to find out more.

There's a huge range of resources available, with over 400 recipes and handy hints on how to use our products.

New - K.Vita. An alternative to keto diets. Contact your health care professional to find out more.

With Vitaflo, you have many options when it comes to managing your diet.

So if you’d like to find out more about the full Keto range of products from Vitaflo, our resources and recipes, and the Connected Care App, visit www.myketogenicdiet.com and/or speak with your health care professional.

And don’t forget that all Vitaflo products are available for free delivery via our Vitaflo to You service!
We are so grateful in these difficult times for the kind support and generosity of you all. Please like and follow us on Matthew’s Friends and @matthewsfriends for up to date news on all our events. Please support us and request an MF fundraising pack today from enq@matthewsfriends.org

WE’D LIKE TO THANK THESE FABULOUS FUNDRAISERS!

PURPLE DAY - MARCH 26TH
To mark Purple Day the Vitaflo head office team wore purple, held a bake sale, a raffle, and a purple quiz to raise awareness of epilepsy.

Doesn’t everyone look great in purple?! We’ve been informed the cakes all went down a treat!

Well done to all involved, we are so thrilled by the amazing effort Vitaflo made on Purple Day and thank you so much for the funds raised for Matthew’s Friends which will be put to very good use supporting those on medically managed Ketogenic diets for epilepsy.

FLYING HIGH AGAIN!
Shenise, from the Footprint team, has thrown herself into (or should we say thrown herself off of?!) another airborne fundraiser for Matthew’s Friends.

On 5th May, after a hectic morning driving between 3 possible venues searching for the right weather conditions, she completed a paraglide off the cliffs at Newhaven!

Shenise said...

‘Matthew’s Friends means so much to me. Epilepsy is a part of my life now. My daughter was diagnosed with it and Matthew’s Friends have helped with advice and just being there to listen. Let’s get them some much needed money to carry on their amazing work.

I do mad things for charity, so far, I’ve Wing Walked & Sky Dived. Both terrifying but so rewarding. I’m scared of heights, so I wanted to be out of my comfort zone. Hence now I’m silly enough to glide over the coast. I appreciate any amount you can donate. Thank you Thank you Thank you. Much love as always.’

Thank you so much Shenise for supporting Matthew’s Friends again. You’re an absolute mad woman but we are so glad you are.

Shenise’s paraglide has so far raised £800 (Plus GiftAid), if you’d like to add your support please click on the link here.
We are so grateful in these difficult times for the kind support and generosity of you all. Please like and follow us on Matthew’s Friends and @matthewsfriends for up to date news on all our events. Please support us and request an MF fundraising pack today from enq@matthewsfriends.org.

If you would like to get involved and help us in any way, please contact the Matthew’s Friends office on 01342 836571, or email enq@matthewsfriends.org. Every penny helps us to make the difference to the many families and Ketogenic centres we support. Please help us to continue our work and extend our services through 2024 and beyond, thank you.

Pamela McCall took part in The Glasgow Kiltwalk on Sunday 28th April to raise funds for Matthew’s Friends.

There are three different lengths of walk and Pamela completed ‘The Mighty Stride’ which is a 23-mile hike starting from Glasgow’s iconic Glasgow Green and finishing in the idyllic surroundings of Balloch, Loch Lomond. It sounds amazing and very challenging!

Pamela’s daughter, Ashley, joined her for the ‘Wee Wander’ on the last 4 miles of the walk.

Pamela had this to say after the trek:

‘Thank you all very much for your donations to our chosen charity Matthew’s Friends Ketogenic Therapies charity. Ashley joined me for the last 4 miles doing her own version of the wee wander. It was a lovely day.’

Congratulations Pamela and Ashley! Thanks so much for taking part in the Kiltwalk and championing Matthew’s Friends in this way – we really do appreciate your support!

Pamela has raised over £700 for our charity for which we are immensely grateful!

You can read more of Pamela’s story here and there’s still time to donate if you can – thank you.

Both Greg Aldridge (our Val’s son) and his cousin Lewis Whatley took part in this year’s Brighton Marathon on Sunday 7th April. Both young men are runners, but the Brighton Marathon is something else, the training and the preparation takes time and dedication for months before hand.

Both did amazingly well completing in under 4 hours!

Between them they have so far raised over £3,000 with GiftAid – an incredible amount for which Matthew’s Friends are immensely thankful!

If you would like to donate to either Greg or Lewis’s fundraising pages, please click on the links below.

Greg and Lewis ran the Brighton Marathon for Matthew’s Friends

This year’s Oxted Pram Race is on Sunday 30th June