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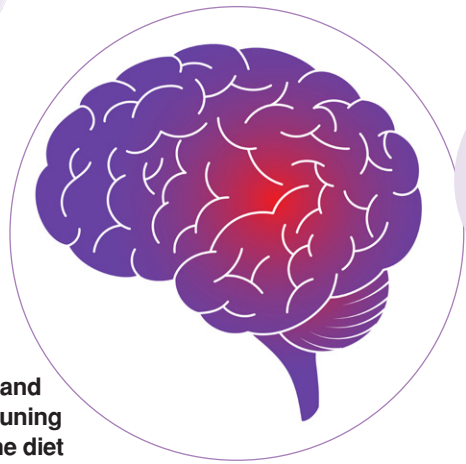
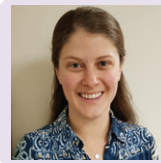
# THE ROAD TO KETO





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**The ketogenic diet (KD) is recommended for children with drug-resistant epilepsy.[3,4] Once a caseload of patients has been built up, the practicalities of managing symptoms and side effects becomes essential. Fine tuning the diet is often key and weaning of the diet becomes important in seizure control.**

Not unlike the stories of a number of my colleagues, much of my journey to a role as a Ketogenic Dietitian at Great Ormond Street Hospital (GOSH) was a series of happy coincidences. Getting into paediatrics in the first place was only thanks to the kind hearts of the adult dietetic team at Milton Keynes Hospital lending me to their desperately short-staffed paediatric department. I loved paeds, so a job at GOSH was the ultimate dream – fortunate for me then, that a change of management in the GOSH department meant that they were recruiting rotational band sixes.

Following rotations with the gastro and cardiac teams, I was on holiday when I got a text from a colleague: "You're rotating to neurology – want to go to Keto College next week?" I returned to work with a renewed passion for dietetics, as ketogenics appeared to offer a perfect combination of what I loved about the job: close MDT working, with the diet as a medical treatment and, therefore, worthy of the attention of some of the top paediatric neurology brains in the world, who just so happened to work at GOSH; an opportunity to develop relationships with families, with roughly half of children with drug-resistant epilepsy seeing at least a 50% reduction in seizures[1] and, therefore, remaining on the diet for around a two-year period before attempting to wean; and the chance to advise on a diet where mayonnaise is encouraged almost without limit. What could be better?

## THE KETO DIET: A POTTED HISTORY

As someone who, at the time, had more knowledge of 'keto' as a diet promoted for weight loss, Keto College, run by Matthew's Friends, was a huge eye-opener. The KD was first proposed as a treatment for epilepsy at the beginning of the 20th century to mimic starvation, following reports in the literature of patients deprived of food having a reduction in seizure activity. Interest in the diet waned in the middle of the last century with the advancement of anti-epileptic drugs (AED); however, AED do not work for all children with epilepsy, and often cause unwanted and occasionally dramatic side effects. Sodium valproate, for example, which the BNFC[2] recommends as the drug of

Table 1: Anti-epileptic drug of choice Sodium valproate: the a-z of side effects

| | | |
|---|---|---|
| Abdominal pain | Haemorrhage | Nausea |
| Agitation | Hallucination | Nystagmus |
| Alopecia (regrowth may be curly) | Headache | Oral disorders |
| Anaemia | Hepatic disorders | Seizures |
| Abnormal behaviour | Hypersensitivity | Stupor |
| Concentration impaired | Hyponatraemia | Thrombocytopenia |
| Confusion | Memory loss | Tremor |
| Deafness | Menstrual cycle irregularities | Urinary disorders |
| Diarrhoea | Movement disorders | Vomiting |
| Drowsiness | Nail disorder | Weight increased |

choice for newly diagnosed tonic-clonic seizures in children, lists a whole range of common, or very common, side effects (see Table 1).

Concerns about epilepsy that is refractory to anti-epileptic medications, along with concerns about the side effects of these medications, led to a rebirth of interest in the KD, spurred on in part by the activism of the Charlie Foundation, a US charity started by the family of a boy with refractory epilepsy who was treated successfully with a KD. Charlie's father, Jim Abrahams, went onto direct the movie …*First, Do No Harm*, starring Meryl Streep, which further piqued public and research interest in the diet.

The diet, however, by no means became widely available and in 2004, two charities, Matthew's Friends and The Daisy Garland, were started in the UK by families who had experienced similar frustrations as Jim in accessing this life-changing treatment for their children. Keto College is run by Matthew's Friends and it is a real honour to be in the presence of Matthew's mum Emma Williams, who speaks so passionately about the benefits of the diet on Matthew's seizure burden and quality of life, and who continues to work tirelessly to make the diet a more accessible treatment option for those eligible children.

International[3] and NICE[4] guidelines now recommend KD for children whose epilepsy has not responded to at least two anti-epileptic drugs, at which stage the condition is referred to as drug-resistant epilepsy. Although, at present, KD is not recommended as an alternative to medications for children whose epilepsy is well controlled with AEDs, a patient survey carried out by Nutricia[6] indicated that KD is seen to have a positive impact on quality of life (QoL) in terms of attention and focus, energy levels and mental ability, where AEDs were generally seen to have negative impacts. However, as things stand, QoL measures are not used as justification to start KD as an alternative to AEDs. I would go on to discover that most of the children referred for the diet at GOSH have tried and failed many more drugs than this, suggesting that awareness and/or funding are still not where they should be.

## CLASSICAL AND MODIFIED KD

Along with learning the history, past and current research and hearing the personal accounts of the benefits of KDs, we also had a practical education in planning and managing KDs. The bulk of the research over the last century has been on the classical KD, which prescribes a ratio (eg, 4:1) of grams of fat to grams of carbohydrates and protein combined. More recent research and practice has been in the use of the modified KD, or modified Atkins diet, which prescribes an approximate percentage (around 65-75%) of dietary calories as fat, with the remaining calories coming from a prescribed amount of carbohydrates (starting at, for example, 30g per day) and essentially 'free' protein. There has been research into the medium chain triglyceride (MCT) diet too, which prescribes a daily volume of MCT oils or emulsions to meet some or all of the dietary fat, along with a prescription for amounts of carbohydrates and protein.


If all this sounds confusing to you, reader, you are at the same baffled stage that I was by the end of day 1 of Keto College! However, following masterclasses by some of the most experienced ketogenic dietitians in the UK, cookery demonstrations by the keto specialist chefs from Matthew's Friends, Vitaflo and Nutricia, and a couple of keto-friendly meals thrown in for good measure (celeriac mash replaced potatoes and double cream was provided in abundance for the conference lunches), I left feeling informed and ready to tackle anything that our complex patient caseload could throw at me.

## MANAGING THE DIET IN PATIENTS

Back at GOSH, I was supported by my senior colleagues, who had several years of KD experience between them, to build up a caseload of patients on classical and modified KD, both enterally and orally fed. Now came the business of managing them. I discovered that, while the initiation of a diet is the first step, the real business of the diet is in the tweaking or 'fine tuning' – improving ketosis if required – while keeping the diet palatable and manageable. I became acutely aware of the importance of regular weight monitoring and discussions surrounding hunger and satiety, as the diet can lead to seemingly unexplainable swings in weight, either gain, or loss. This is despite taking into account current seizure activity or reduced mobility due to developmental delay when calculating estimated requirements. While the dietitians work hard to control these weight discrepancies, occasionally this is a reason why the diet cannot be continued beyond the initial three-month trial period, or must be put on hold while weight is stabilised.

Side effects are managed, such as constipation and reflux, and less common side effects, such as poor bone health and kidney stones, particularly when used alongside certain medications, are monitored and minimised. The diet is almost always supported using a low-carbohydrate multivitamin and mineral supplement (if accepted), as, realistically, it is difficult or impossible to achieve the recommended five-a-day of enough of a variety of fruits and vegetables to ensure a balanced diet. Nutritional bloods are monitored and supplements prescribed accordingly.

Beyond the actual practicalities of the diet, I began to realise that we also played a role in supporting the emotional wellbeing of families of complex children. Feeding can be extremely stressful at the best of times for the family of an unwell child. Combine that with anxieties surrounding ketone levels, difficulties managing worsening constipation,

the mathematical logistics of KD ("If 100g of hummus contains 14g of carbohydrates, then how many grams of hummus can my child have alongside 45g of carrot sticks to meet their 8g carbohydrate allowance? And does the fat in the hummus count towards their fat choices?"), and the struggles of nut-free schools for a diet where nuts can be the best portable snack option, and you have a recipe for a disaster without proper support.

Fortunately, I have heard more excellent feedback about my senior colleagues than I have ever heard negative – a mum at the Young Epilepsy Research Retreat in January of 2020 described the dietitians as her "lifeline"; and the walls of the office are plastered with Christmas cards and Thank You cards from happy families.

## TRYING IT FOR MYSELF

I have given the diet a go (modified KD, 5g carbohydrate, four fat 'choices' each equivalent to 10g fat, and unrestricted protein per meal) and can imagine wanting support just with meal ideas aside from anything else. Fortunately for me, when trying the diet, and for our families, there are a great many more online resources and suitable ketogenic products available these days than when Charlie, Matthew or Daisy's parents were trying the diet. From carbohydrate-free rice and pasta alternatives made from konjac flour; to plant-based milk alternatives, sugar-free versions, which tend to be carbohydrate free, not to mention, of course, the now ubiquitously available avocado, favourite of millennials and keto kids.

The most recent step in my KD journey has been to take on a full-time position in the team, which has meant an increased caseload of KD patients, as well as more insight into the running of the service and the challenges this can entail. I have had the opportunity to hear about the fascinating research happening in the world of Young Epilepsy and how the KD and other diet-related options, such as MCT supplementations, fit into that.

I have learnt more about managing periods of illness while on the KD and how to fine tune the diet for patients who remain on a KD for longer than the usual two-year period. I've learnt about weaning of the diet at the appropriate time too; the literature suggests that in 80% of cases, seizure reduction is maintained on weaning of the diet.

There is a strong community of dietitians in groups such as the Ketogenic Professional Advisory Group (KetoPAG) and the Ketogenic Dietitians Research Network (KDRN)[5] and I look forward to a future that engages with other services. It will be great to hear about how the diet is being delivered across the country and, indeed, across the world.

So, here's to the next step: collaboration and sharing of ideas, preferably over some keto friendly snacks . . . Olives and salami anyone?

References

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| Questions relating to: *The road to keto*<br>*Type your answers below, download and save or print for your records, or print and complete by hand.* | |
|---|---|
| Q.1 | What are some of the issues surrounding anti-epileptic medications? |
| A | |
| Q.2 | When is the KD recommended for children with epilepsy? |
| A | |
| Q.3 | What evidence is there of the benefits of the KD for children in this cohort? |
| A | |
| Q.4 | Explain the differences between the classical KD and the modified Atkins diet. |
| A | |
| Q.5 | How does the medium-chain triglyceride diet benefit patients? |
| A | |
| Q.6 | What does dietetic management of the KD involve? |
| A | |
| Q.7 | How are side effects managed? |
| A | |
| Q.8 | Explain how the diet is supported to ensure nutrient sufficiency. |
| A | |
| Please type additional notes here . . . | |