

EPILEPSY AND KETOGENIC DIET THERAPY: MANAGING EXPECTATIONS IN PATIENTS



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In the first of our new IMD columns from the NSPKU, Kit Kaalund Hansen looks at Ketogenic Diet Therapy as a dietary management for patients with epilepsy. Many assume that the ketogenic diet will fast track them to a seizure-free lifestyle and, whilst reducing seizure activity and improving overall quality of life are the ultimate goals of specialist therapy, the complexity of the diet and the gargantuan commitment is often, if not always, undermined.¹

Ketogenic Diet Therapy (KDT) is considered a medical treatment and must be complied with every minute, of every day, on all occasions, in the same way that patients must keep taking their prescribed anti-epileptic medications.² If you miss a dose and the equivalent in dietary terms, treatment is less likely to be successful. In most cases, taking a pill is much easier than weighing, measuring and recording every ounce of calorie you consume.

So, how can we manage our patients' expectations, so that they can make an informed decision as to whether KDT is suited to their lifestyle? Also, what is our responsibility as healthcare professionals to ensure the continued safety of the patient?

DON'T HIDE THE FACT THAT KDT MIGHT NOT WORK FOR THEM

A review of multiple studies concluded that KDT may be successful for 50% of adults with epilepsy by reducing seizures and/or seizure duration and/or recovery time by 50%, hence improving quality of life.³ The hope is that KDT will improve memory, concentration and overall energy levels along with some seizure control. If KDT is unsuccessful, the changes will take effect relatively quickly.¹ A three-month trial is generally sufficient to indicate whether the impact on quality of life makes KDT worth pursuing longer term.

WHO IS A KETOGENIC DIET THERAPY FOR?¹

The Modified Ketogenic Diet is appropriate for those settled at home and able to feed themselves, cook, shop and make their own informed choices.

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

MEDICAL SCREENING (NEUROLOGIST OR GP)^{4,5}

Make the patient aware that they might not be suitable

Some conditions might make a ketogenic trial unsuitable or even hazardous. It is also important that lipids, various vitamins, minerals and functional markers are checked at baseline before commencing a prescribed ketogenic regime. These are then checked again at three and 12 months to monitor any potential change. If the changes are deemed significant and a threat to the wellbeing of the patient, KDT must be stopped immediately and an appropriate weaning plan put in place.

A CONSIDERABLE CHANGE TO EATING HABITS⁶

Assess food preferences and dislikes

Ensure that the patient does not underestimate the commitment they are about to make. KDT commonly involves a significant shift in food choices and the

Kit has spent three years exploring the ever-changing specialist area of inborn errors of metabolism. In late 2015, she was fortunate to become the first NHS funded Ketogenic Dietitian for adults with epilepsy in the UK.



CONTRAINDICATIONS:

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

CAUTION:

- Dysphagia (swallowing problems)
- Gastro-oesophageal reflux and a history of severe constipation need to be appropriately managed prior to initiation
- Diabetic on medication

way meals look. As with any significant change in diet, it is more difficult to make the switch all in one go. Therefore, I tend to encourage 'step-down' preparation for one to two weeks in advance. In this way, the patients have a chance to try out new recipe ideas and become familiar with the basic principles, weighing and measuring, specific dietary sources of fat and foods low in carbohydrates etc. The aim is to make the final changeover much easier to cope with.

COOKING MEALS FROM SCRATCH⁶

Always account for the patient's abilities and limitations

Are they safe to cook? Are they good with numbers? Are they committed? Ready-meals are rarely available and not many shop bought snacks are 'keto-friendly'. Meals generally need to be prepared from fresh with raw ingredients and, therefore, a willingness to cook is essential. Planning ahead and food preparation is key. Patients need to be acceptant of the fact that keto-friendly meals cannot be shared with other members of their household, as this is a medical diet and suitable for them only.

CAREFUL RECORD KEEPING⁷

KDT is labour-intensive and often tedious

Throughout the first three months of treatment, it is essential that patients record daily fat and carbohydrate exchanges, twice daily blood ketones and glucose, any seizure activity and weekly weights. You will find that the level of commitment becomes clear very quickly.

ADAPTATION TO LIKELY FREQUENT CHANGES TO YOUR DIETARY REGIME⁷

Prepare for dietary changes along the way

KDT is entirely individualised and the patient's dietary prescription will need adjustment along the way. This adjustment depends on the individual's records of seizures and associated symptoms, blood ketone/glucose levels and weight change.

SUPPORT NETWORK⁸

Investigate the patient's social circumstances

Radically changing eating habits can be tough under any circumstances, but KDT is much more than this. The patient becomes responsible for delivering their own treatment, monitoring its effects and making it work with the supervision of a specialist dietitian. It is essential that the patient is ready to take responsibility for their actions as KDT can be empowering, overwhelming and worrying all at the same time. Moral and practical support from those around them is of great importance.

For more information on the work of The National Society for Phenylketonuria (NSPKU) visit www.nspku.org/
For more information and support on Ketogeneic Diet Therapy: National Hospital for Neurology and Neurosurgery NHNN www.uclh.nhs.uk/OurServices/OurHospitals/NHNN/Pages/Home.aspx
Matthew's Friends www.matthewsfriends.org/

References

- 1 Kossoff EH, Dorward JL. The modified Atkins diet. *Epilepsia*. 2008, 49(Suppl 8) 37-41
- 2 Lefevre F, Aronson N. Ketogenic diet for the treatment of refractory epilepsy in children. A systematic review of efficacy. *Pediatrics*, 2000, 105 E46 1-7. 23
- 3 Levy R, Cooper P. Ketogenic diet for epilepsy. *The Cochrane Library Issue 3*. Chichester, UK: John Wiley, 2004
- 4 Delgado MR, Mills J, Sparagana S. Hypercholesterolemia associated with the ketogenic diet. *Epilepsia*, 1996, 37(Suppl 5) 108
- 5 Nizamuddin J, Turner Z, Rubenstein JE et al. Management and risk factors for dyslipidaemia with the ketogenic diet. *J Child Neurol*, 2008, 23 758-61
- 6 Greene AE, Todorova MT, Seyfield TN. Perspectives on metabolic management of epilepsy through dietary reduction of glucose and elevation of ketone bodies. *J Neurochem*, 2003, 86 529-37
- 7 Kossoff EH, Zuppec-Kania BA, Vining EP et al. Optimal clinical management of children receiving the ketogenic diet: recommendations of the International Ketogenic Diet Study Group. *Epilepsia*, 2009, 50 304-17
- 8 Eltze C, Fitzsimmons GJ, Sewell M et al. Great Ormond Street Hospital: Clinical Guidelines for the Ketogenic Diet, 2010. www.gosh.nhs.uk/health-professionals/clinical-guidelines/the-ketogenic-diet-in-the-management-of-epilepsy. Accessed 31 October 2012.