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The Modified Atkins Diet for seizures - the experience of a ketogenic novice by Susan Wood RD

Since the 1920's there has been evidence that ketogenic diet regimes can radically influence seizures patterns and transform the lives of those blighted by epilepsy. However, the discovery of anti epileptic drugs sidelined the diet treatment for decades. The diet option experienced a resurgence in the early 1990's after the studies of Dr John Freeman at John Hopkins Institute, Baltimore found that it produced complete seizure control in 30 percent of children with drug resistant seizures, and that an additional 38 percent showed a marked improvement.

In the UK, Ketogenic diets have only been offered as a treatment to a relatively small number of children whose seizures cannot be controlled by medication alone. As a result, essential medical and dietetic expertise is concentrated in the children's hospitals and a few specialist children's departments in large hospitals. Therefore, the option to try a ketogenic diet treatment is limited and most centres have a waiting list. Once people with epilepsy reach the age of 18 and transfer to adult care, the door to ketogenic diet treatment is firmly closed. However in other parts of the world such as USA and South Africa, adults still have a chance of receiving dietary treatment with novel ketogenic regimes such as the Modified Atkins Diet (MAD).

Why is the Modified Atkins Diet different?

The traditional ketogenic diet prescription is based on a child's daily energy and protein requirement and provides a carefully calculated ratio of fat, protein and carbohydrate (such as 4 grams of fat to each 1 gram of protein plus carbohydrate) at all meals and snacks. The diet forces the body to metabolize fat as the primary energy source; resulting in the production of ketones. It is still not fully understood how this treatment works but ketones are thought to be the key as they have an anticonvulsant effect and ketosis leads to a number of alterations in brain metabolism. Fasting or a restriction in calorie intake can also have a similar impact.

The MAD appears straight forward by comparison. It carefully controls carbohydrate intake, encourages fat and does not restrict protein or total energy intake. The practical anticonvulsant value of the Atkins Diet came to light when the parents of a child who was one month away from her scheduled hospital admission to

commence the ketogenic diet started to follow Dr Atkins' New Diet Revolution in preparation for her imminent treatment. Within two days her seizure rate went from 70-80 per day to zero. She was producing large amounts of ketones in her urine (a marker used for any ketogenic regime) and her carbohydrate intake had dropped to approximately 10grams per day. This little girl then continued on the Atkins Diet and ultimately managed to reduce her seizures by more than 90% and half her dose of anti epileptic medications. Subsequently Eric Kossoff and his team at the John Hopkins Institute in Baltimore USA ran trials for adults and children with a modified version of the Atkins Diet. These have produced very encouraging results.

The dietitian's story

I work part time for a small dietetic team in South Staffordshire PCT. In March 2008 we received a referral from our visiting Neurologist for a 22 year old male patient with intractable epilepsy. Could we start treatment with the MAD? We had no knowledge of this particular regime but were aware of ketogenic diets for epilepsy and the level of dietetic expertise (and dietetic time!) required to oversee them. We felt ill equipped to manage the case so referred the patient on to the nearest acute hospital team. However, the referral bounced back to us a couple of months later because they also felt unable to fully tackle the treatment. I volunteered to look into it and spent one very late night surfing the internet. I found the Matthews Friends website and read all about the MAD regime. I also watched the video of a dietitian's (from USA, UK and South Africa) meeting where Emma Williams the founder of the charity asked "Why are dietitians SO afraid of ketogenic diets?" The experienced ketogenic dietitians answered truthfully and eloquently (time, experience, fear of the unknown etc) but I must have taken Emma's words as a personal challenge because it was then that I decided I must at least have a go and that it would have to be predominantly in my own time. After countless hours of internet research and numerous phone calls to ketogenic centres around the UK, I was amazed to find no one treating adults. I did however obtain lots of helpful guidance from expert ketogenic dietitians at the Children's Hospitals in London, Glasgow and Birmingham, some of which had used the MAD regime with older children. Subsequently I have made contact with dietitians in the USA and South Africa who have plenty of experience treating adults with the MAD.

Getting started After initial phone conversations with mum to gather background information and chat through the implications of the treatment I finally met Tom and his family in July 2008 to discuss the practicalities. Food diary analysis indicated a very normal distribution of food energy sources (Table1) that would need to change significantly! We discussed meal adaptations, and mum (assisted by daughter Amy), set about drafting menus based on these. One of our biggest concerns was that Tom may lose weight. His BMI at the outset was 18.4kg/m^2 and he was already self conscious about his leanness so we wanted to avoid weight loss at all costs. That was why I decided to prescribe fat portions throughout the day – to ensure an

adequate calorie intake.

Baseline biochemistry was carried out and the GP kindly prescribed Calogen, Liquigen, Phlexyvits, Ketostix for urine and blood ketone testing strips for a machine kindly supplied by our diabetes specialist nurse.

In the first two weeks, Tom's seizures (particularly on waking) continued with no change but there was a significant improvement in Tom's energy levels, general alertness and zest for life. He became more interested in being with the family, chatting and generally doing things. He even started answering the phone which was quite out of character! Prior to the diet change, a bad seizure would have wiped him out for the whole day but now his recovery was remarkably rapid and most times his day could then continue as planned. In the early weeks, we introduced Movicol to manage the constipation – a common side effect of the diet and made a couple of attempts to introduce the recommended vitamin supplements. Unfortunately the latter coincided with significant adverse changes to Tom's seizure pattern so we have left these for now.

Surprisingly his diet (Table 2) is currently providing >100% of his Reference Nutrient Intake (RNI) for all nutrients other than potassium which is 87% of his RNI.

By the end of August we were noticing dips in the blood ketone level (from 2-3mmol/l range to 0.7-2 mmol/l) and Tom seemed to go through a bad patch. I had read reports about the use of L-Carnitine supplements to lift the ketone levels so after clearing it with the neurologist and GP we started supplements in September. The ketone levels then rose quite rapidly to 4.2mmol/l at one point and the overall response was quite dramatic and frightening (we had been warned!). Subsequently we lowered the total dose and distributed it more evenly through the day but we will try increasing it again soon. Recent blood tests have shown an increased cholesterol level and we plan to lower the fat (energy) intake at some point but we are currently tapering one of his drug doses and the golden rule is to only change one thing at a time.

Tom's treatment is still evolving and although he has some seizure free days and the pattern has altered, his seizure count has not really changed significantly. However Tom and his family feel that the improvement in energy levels and wellbeing make the diet treatment worth pursuing. We are slowly making adjustments and learning more as we go along. His mum and I have moved from daily phone calls at the beginning through to speaking twice a week with the odd e-mail here and there. We could not have managed without a lot of help from experienced ketogenic dietitians, many of which I have found via the Matthews Friends Website.

The future?

Surely there is now sufficient evidence to warrant the provision of dietary treatment options for adults with intractable epilepsy in the UK. Ideally the treatments should be supported by a multi disciplinary team including a dietitian, neurologist and specialist epilepsy nurse. Tom's MAD challenge has provided me with the most rewarding experience of my 27 years in dietetic practice and I am aware of three further adult

dietitians (London, Birmingham and Edinburgh) who are preparing to start young adults on this regime soon.

Are there any more adult dietitians out there who would like to have a go?

The mother's story

My son Tom was diagnosed with epilepsy at the age of 6. He is now 22 and over the intervening years the treatment for his epilepsy has meant countless EEG's and scans, 15 medications in varying combinations and a vagal nerve implant. Tom has not only suffered as a result of his numerous daily seizures but also from the medications given in vain attempts to quell them. Over the years he seemed to acquire many of the potential drug side effects, which took their toll physically, mentally and emotionally.

In early 2008 our consultant neurologist suggested that we were running out of further drug options so how about trying a Modified Atkins Diet (MAD) to help control Tom's many seizures? I remember enquiring about the ketogenic diet when Tom was about ten but was told it was unsuitable for him and that there was a lack of evidence to support its use. After years of struggling with Tom's epilepsy, the countless hospital appointments, the disrupted education and the impact on family life in general (we also have a daughter just 2 years younger than Tom) we were more than eager to give the Modified Atkins Diet a try. Tom was particularly thrilled that he could have some sort of control over his treatment. We had nothing to lose!

I am not really very confident in the kitchen but I have always prepared a home cooked evening meal for the family and we always tended to eat together. Tom has never been a big eater but with closer scrutiny of his diet, we realized that Tom didn't eat as much as he could because he struggled to eat and chat about his day at the same time. Once he was on the Modified Atkins Diet he saw it as his task to finish his meal and he felt better able to do this in private. Since this decision was made Tom eats his meals in his room and feels a great sense of achievement.

Starting the diet is scary as it seems to go against all that we believe is right. High fat!! We keep a record of food (fat and carbohydrate portions), urine ketones, blood ketones, seizures etc to help us track Tom's progress. Tom has now been on the MAD for six months and it has certainly been a rocky road. Between his sister Amy and me we have come up with some interesting meals for Tom and we look at food in a different light now. All four of us feel that there has been a definite improvement in Tom's well being, even though the average number of seizures has not altered much so far. He is enjoying taking control and his seizure pattern and recovery time has changed. We hope over time it

will improve even more. This diet could not, in my opinion, be administered without full support of our wonderful dietitian who has lifted our spirits and given freely of her time and expertise.

Tom's view

So far the diet has made an improvement and it has helped with other things also. I'm eating better and more. My head has been clearer and when I do have a fit I seem to recover quicker. I feel more confident standing in the shower without worrying about having a fit. Chocolate tastes nice but it doesn't do anything good for you so I don't mind. Sometimes it can be difficult but if it helps me with my fits it will be worth it. My parents give me a lot of support.



Tom and his sister Amy



One of Tom's many EEG's

Sources of further information on the Modified Atkins Diet and ketogenic diets in general

Matthews Friends

<http://site.matthewsfriends.org>

The charity Matthews Friends was launched in April 2005 to publicise and support ketogenic diet treatments for epilepsy. The charity provides a wealth of practical ketogenic diet information and a support network for families coping with the treatment. They also provide excellent training days for dietitians, doctors, nurses and parents / carers.

The following excellent references are easily accessed on this site:

The ketogenic diet: From molecular mechanisms to clinical effects_ - Conference review

Freeman J, Veggiotti P, Lanzi G, Tagliabue A, Perucca E.
Epilepsy Research 68 (2006) 145–180

A modified Atkins diet is effective for the treatment of intractable pediatric epilepsy

Kossoff E.H., McGrogan J.R., Bluml R.M., Pillas D.J., Rubenstein J.E., Vining E.P.
Epilepsia, Feb 2006, 47/2(421-424).

A prospective study of the modified Atkins diet for intractable epilepsy in adults.

Kossoff E.H., Rowley H., Sinha S.R., Vining E.P.G.
Epilepsia, Feb 2008. 49/2(316-319).

The use of L-Carnitine – Latest Findings From Elizabeth Neal RD, Phd.

The Charlie Foundation

<http://www.charlifoundation.org>

United States support group for those on ketogenic diets.

Atkins for Seizures

<http://www.atkinsforseizures.com>

A helpful US website set up by Michael Koski, the father of a child who took part in one of the early Modified Atkins Diet trials. From this website you can purchase an e-book (150 pages!) which charts their experience (the good and the bad) of managing their daughter's diet regime —what they have found helpful and how they managed problems. Very honest and practical.

The Ketogenic Diet – A treatment for children and others with epilepsy(4th Edition)

Freeman, Kossoff, Freeman & Kelly. Publisher Demos

Written by the US team who have led world research into ketogenic diets and epilepsy. A detailed overview of ketogenic diets with a single chapter devoted to the Modified Atkins diet.

The ketogenic diet for the treatment of childhood epilepsy: a randomised controlled trial.

Neal EG, Chaffe H, Schwartz RH, Lawson MS, Edwards N, Fitzsimmons G, Whitney A, Cross JH.
Lancet Neurol. 2008 Jun;7(6):500-6.

The first randomised controlled trial to examine ketogenic diets.

Dr Atkins New Diet Revolution (PLUS Various Atkins recipe books)

Dr Robert C Atkins. Publisher Vermillion

Useful background information about the science behind the Atkins diet. Recipes may be helpful for ideas.

Table 1

