

Ketogenic Diet versus Drugs

This is the personal account from a parent whose child has epilepsy (name changed). It is a detailed account of the history of drugs that were prescribed and the results they witnessed from these. Then the account continues with how the Ketogenic Diet provided a positive alternative to all these drugs. It is not a medical paper but a diary of events and personal opinions.

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MARCH 1999

Tim develops epilepsy in the form of atypical absences. These are like sleepwalking, but with the tendency to fall as well.

*Treatment: NO DRUGS
NO DIET*

JUNE 1999

Tim is put on a low dose of Epilim, due to increase gradually over time until we reach a therapeutic level.

*Treatment: LOW LEVEL EPILIM
NO DIET*

AUGUST 1999

Tim is now on a higher dose of Epilim. His atypical absence seizures have gone, but he develops a new type of seizure – myoclonic jerks.

*Treatment: MEDIUM LEVEL EPILIM
NO DIET*

SEPTEMBER 1999

Tim starts school, and hates it. His seizures are making it hard for him to focus and the drugs are starting to make him clumsy. With hindsight, it is likely that he was also experiencing sub-clinical absence seizures, which affected his concentration. His teacher is totally unsympathetic and mocks him in front of the other children. His self-esteem plummets. Fortunately there is a lovely classroom assistant to ameliorate the situation. Despite the problems, his baseline assessment is very promising.

*Treatment: MEDIUM LEVEL EPILIM
NO DIET*

2000 - 2002

Tim slowly deteriorates over time. His myoclonic seizures increase in severity and frequency. We try three other drugs separately in combination with the Epilim (Clobazam, Ethosuxamide and Lamotrigine), but they either have no impact on the seizures, or worsen them significantly. He is now having atypical absences again. Our consultant tells us that it will be very difficult to find a drug that will work for Tim's epilepsy type, which is rare.

*Treatment: HIGHER LEVEL EPILIM
NO DIET*

SEPTEMBER 2002

Tim is on a very high dose of Epilim for his age. His hands shake with the high level of Epilim and his handwriting/fine motor skills are adversely affected. Fortunately this is a temporary effect and it seems to wear off as we reduce the dose at a later stage. We introduce Topiramate, a new drug. The consultant informs us that if this drug does not work then there are no other appropriate licensed drugs left for us to try. Tim deteriorates rapidly and begins to wear a helmet at school. The seizures have become so severe that the force of them breaks a couple of dinner plates. After a fortnight we make the decision to slowly withdraw this drug, with the agreement of our consultant. We also ask to be considered for the ketogenic diet. Over the next year he will fall down the stairs several times, nearly drown in the bath and smash head first into a bookcase, amongst many other accidents. He receives a statement of special educational needs because of his medical condition.

*Treatment: HIGH LEVEL EPILIM
NO DIET*

SEPTEMBER 2003

Tim is gradually getting worse and worse. The seizures have changed to the point that the EEG technician can no longer give us a firm diagnosis. There is not enough funding for Tim to start the diet at St Georges, so we are referred to Great Ormond Street. There is no question that Tim is a perfect candidate for the medical trial being conducted there. He has numerous seizures that the drugs have completely failed to cure. We are at our wits end. Most damaging to his education are the absence seizures and the likely sub-clinical activity that prevent him from concentrating and learning normally. He has fallen far behind his peers. Most damaging to him physically are the violent myoclonic jerks, which he endures on a daily basis. He has a wonderful, caring SNA, without whom he would not have made it through the first two years of junior school.

*Treatment: HIGH LEVEL EPILIM
NO DIET*

FEBRUARY 2004

Tim finally starts the MCT version of the ketogenic diet, under the supervision of the medical team at GOSH. Within a week of starting the diet, it is as though a light has been switched on inside his head. He begins to respond to people more readily, to laugh, and to read more fluently. It is very clear to everyone that Tim is a very different child. The number of myoclonic/obvious seizures does not decrease significantly over time but Tim's alertness is undoubtedly improved, probably due to the suppression of previously unsuspected or sub-clinical seizure activity.

*Treatment: HIGH LEVEL EPILIM
MCT DIET*

MAY 2004

As it is clear that Tim has already benefited hugely from the diet, the consultant agrees for us to reduce the drugs. We calculate it will take us several months, and we learn later that children can respond very badly to drug withdrawal, with increased seizures and behavioural deterioration. We are determined to go ahead with the program.

*Treatment: EPILIM REDUCING in quite large increments
MCT DIET*

JULY 2004

The withdrawal program is proving to be a rough ride for Tim. His seizures are longer, on occasions, than they have ever been (up to 3 minutes in duration).

*Treatment: EPILIM REDUCING in large increments
MCT DIET*

AUGUST 2004

The mother of a little girl (with the same diagnosis as Tim) who has been rendered seizure-free by the ketogenic diet recommends that we reduce the drug very, very slowly, so we switch to the liquid version of the drug and decrease by 8mg a day. Tim stops having the severe withdrawal seizures and the daily seizures start to diminish in length.

*Treatment: LOW DOSE EPILIM REDUCING very gradually
MCT DIET*

SEPTEMBER 2004

Tim takes his last dose of Epilim. At this point the myoclonic jerks are back to their original form – very mild and short lasting. The absences seem to have vanished for the time being as well. Tim is quite bright and alert, better than he has been for 3 years or so.

*Treatment: NO DRUGS
MCT DIET*

DECEMBER 2004

Things begin to go wrong with the diet. Tim seems unable to tolerate the MCT version any more and struggles to finish his meals and to consume the prescribed daily calories.

Over the Christmas holidays he deteriorates and we observe tonic clonic seizures, which we have never seen before.

*Treatment: NO DRUGS
MCT DIET*

JANUARY-JULY 2004

Tim has some very rough patches. His seizures are frequent and prolonged and he continues to struggle to eat everything. Meals take forever to finish. The absence seizures return, as does the sub-clinical activity. He finds it difficult, once more, to focus and concentrate and his behaviour deteriorates. He has an EEG in April, which reveals seizures occurring about 40% of the time and post-ictal in between. This can be mistaken for Non-Convulsive Status without EEG confirmation and is just as difficult to cope with. Children with NCS can appear to function normally in some ways, but cannot learn anything new, etc. In between the bad patches Tim is also better than he has ever been during the day (for example during the Easter holiday), but has long periods of seizure activity at night as his brain is trying to get from Stage 2 to Stage 3 sleep (moving from light sleep to very deep sleep where the wave-form is slow and real rest can occur). One night it takes 6 hours for him to get through Stage 2 sleep (During normal sleep this Stage lasts between 5-15 minutes). On a number of occasions we use diazepam to try to stop these seizures, but with only mixed success. He is shattered a lot of the time and has several prolonged periods of illness including 2 severe ear infections and a bout of impetigo/ringworm. We learn later that this inability to fight off the viruses is likely to have been due to a lack of calories.

*Treatment: NO DRUGS except 5 days of Clobazam as a rescue med in April and occasional diazepam.
MCT DIET*

JULY 2005

At the end of a reasonable weekend Tim suddenly hits a brick wall. On Sunday afternoon July 3rd he starts to have tonic-clonic seizures interspersed by periods of heavy sleep. We start him on Clobazam again to see if this will rescue us, but it does nothing. On Monday 4th this continues and he falls and cuts his head open which sends us to East Surrey A & E. On Wednesday 6th he returns because the seizures are no better and we realise that he is constipated, which exacerbates seizures. After formal admission to Outwood Ward at East Surrey Hospital a cocktail of one-off, strong drugs (Diazepam, IV Lorazepam, Paraldehyde, IV Phenytoin) stop the worst of the seizures for 12 hours only and reduce him to a deep coma. However, as he becomes more wakeful they return in force. He continues on a maintenance dose of Phenytoin and is started on Heminevren, a drug used to help alcoholics to overcome their addiction, but this does not help at all. He can only communicate with us by blinking or putting a thumb up or very occasional single words. The seizures persist and it is clear that the drugs are not solving the problem and will not assist in the long-term day-to-day management of the epilepsy. The medics at East Surrey admit they are out of their depth.

*Treatment: HUGE QUANTITIES OF DRUGS
MCT DIET VIA NASO-GASTRIC (NG) TUBE/FASTING*

JULY 15th 2005

On Friday 15th he is admitted to GOSH. We make the decision to switch to the classical version of the diet (Long Chain Fats instead of Medium Chain), so the dietician initiates this immediately. As the new diet settles in and the calories are gently increased, Tim begins to come to life again. His communication improves and he has longer and longer periods of seizure freedom. The Heminevren is withdrawn. He is still on a maintenance dose of Phenytoin, but it is recognised that this is not preventing seizures, only preventing the withdrawal seizures, which would arise if we removed it at this stage. Each day he improves a little.

*Treatment: PHENYTOIN/ HEMINEVREN REDUCED AND REMOVED
CLASSICAL DIET VIA NG TUBE*

JULY 23rd 2005

Tim is discharged from GOSH. For the last few days he has been very lively and bright and quite chatty. The consultant is relieved that the problem seems to have been a dietary one. He is no longer on Heminevren but continues on a maintenance dose of Phenytoin. The dose is calculated according to the body weight of the child and would be the starting dose for a child commencing taking this drug. It is nowhere near a therapeutic dose. It is recognised to have possible side effects such as twitching/jerking, and it can exacerbate tonic seizures, which we are definitely seeing. It may also increase blood glucose levels, which will interfere with the efficacy of the diet. Information gathered from the drug information page on the Epilepsy Action website tells us that Phenytoin is not appropriate for absence seizures. His improvement in hospital and subsequently in terms of atypical/typical absences therefore cannot be attributed to the Phenytoin, but the regulation of the diet.

*Treatment: PHENYTOIN maintenance dose
CLASSICAL DIET*

AUGUST 2005

Tim slowly improves until he no longer has daytime seizures, though they still occur during Stage 2 sleep. We have now learned a lot more about the diet and understand that this could be merely a question of fine-tuning (e.g. reducing calories/changing ratio of fat/carbohydrate, eating meals at different times). The blood ketone/glucose readings settle down and become more predictable. At the end of August we reduce the Phenytoin from 175mg a day to 150 mg. We have one day of withdrawal seizures, which vanish within 24 hours.

*Treatment: PHENYTOIN LOWER DOSE
CLASSICAL DIET*

SEPTEMBER 2005

In an effort to try to get rid of the nighttime seizures we increase the calories based on an incorrect assumption and Tim deteriorates. He falls in the playground at school and hurts his head badly. Over the next few days we reduce the calories again and he regains his stability. Generally Tim settles into deep sleep within 90 minutes at present. He is therefore still quite tired during the day.

*Treatment: PHENYTOIN SAME DOSE
CLASSICAL DIET small changes*

SEPTEMBER 21st 2005

We make a further reduction to the Phenytoin (now down to 125mg). We have one withdrawal seizure on Friday 24th September and some aggressive behaviour, but no other problems. The Phenytoin twitches have now gone. Tim is brighter and very cheerful, though he has a dreadful cold. The nighttime seizures are far shorter, and Tim seems to be in Stage 2 sleep for shorter periods.

*Treatment: PHENYTOIN 125mg – VERY LOW DOSE
CLASSICAL DIET NO CHANGES*

SEPTEMBER 25th 2005

Tim has had no daytime seizures at all and no drug-induced twitching. His cold is still quite severe but he is full of good humour and responding like lightning to us. He sings and plays music today by following the printed page, something he could not have done pre-diet. He reads “The Enormous Crocodile” to me without assistance, without hesitation, and with an assortment of amusing voices. He is almost like the Tim we knew pre-epilepsy.

*Treatment: PHENYTOIN 125mg
CLASSICAL DIET NO CHANGES*

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For help and information regarding the Ketogenic Diet please visit the web site:

<http://www.matthewsfriends.org>

There you will find advice, friends and help.