Ketogenic Dietary Therapies for Epilepsy

and other neurological and metabolic disorders

MATTHEWS FRIENDS

Ketogenic Dietary Therapies

Information • Training • Research • Support

Registered Charity No. 1108016

www.matthewsfriends.org

> I AM VERY PROUD OF THE WORK WE HAVE DONE SO FAR IN MAKING THIS TREATMENT MORE WIDELY AVAILABLE FOR ALL THOSE WHO SHOULD NEED IT.
>
> *EMMA WILLIAMS MBE*
> *FOUNDER/CEO – MATTHEW'S FRIENDS*

Our Mission

….is to make Ketogenic Dietary Therapy a treatment option available to all children and adults who may benefit from it:

- To raise public and professional awareness of ketogenic dietary therapy as a treatment option for epilepsy, metabolic and other neurological disorders.
- To provide families and patients with up to date, evidence based information to support informed decision making around ketogenic dietary therapy choices.
- To support families and patients through their dietary therapy journey.
- To support professionals in their administration of dietary therapies by way of literature, ketogenic starter packs and printed materials, educational conferences and training meetings and providing funding, where possible.
- To support clinical research into ketogenic therapy for serious medical conditions.

We thank the Matthew's Friends Medical Board for working with us and supporting us in our mission.

NICE Guidelines 1.12.1 state:

"Refer children and young people with epilepsy whose seizures have not responded to appropriate anti-epileptic medication to a tertiary paediatric epilepsy specialist for consideration of the use of a ketogenic diet."

The Ketogenic Diet (KD)

Introduction

The ketogenic diet is more than its title suggests - it is NOT some fad diet that is currently 'fashionable'. It is a proven medical therapy for epilepsy based on a diet that is high in fat, adequate in protein and low in carbohydrate.

It should be managed by a qualified ketogenic dietitian in partnership with neurologists/doctors. It is clinically proven to be highly effective in managing difficult to control epilepsies, as well as metabolic disorders such as GLUT1 deficiency, with research currently being conducted looking at the diet as a therapy for a range of long term neurological diseases and cancer.

History

The diet was first developed in the USA in the 1920's and was used for children and adults. With the advent of newer anti epileptic medication in the 1930's-1970's interest in the diet waned. The 1990's, however, saw a resurgence of interest in the diet for children. In the 1970's the MCT (medium chain triglyceride oil) version of the diet was also introduced.

Ketogenic Therapy

All types of diet are based on regular fresh food ingredients; meats, fish, eggs, nuts, seeds, cheese, vegetable oils, butter, cream, vegetables and fruits.

- **Classical KD**- where carbohydrate, fat and protein amounts are all measured and carefully distributed to maintain a similar balance (ketogenic ratio) at meals and snacks.
- **MCT KD** - where carbohydrate, fat and protein amounts are all measured and medium chain triglyceride oil e.g. refined coconut oil is included with each meal / snack. This enhances ketosis and allows more carbohydrates.
- **Modified Ketogenic Diets (including the Modified Atkins Diet protocol)** - not so restrictive on protein foods but requires measurement of carbohydrate foods and adequate portions of fats at meals.
- **Low Glycaemic Index Treatment** – very similar to the Modified Ketogenic Diet approach in terms of measuring carbohydrate and encouraging fats but restricts the carbohydrate sources to those with a glycaemic index of 50 or below.

> "
> KETOGENIC DIETARY THERAPIES CAN BE ADMINISTERED AS A NORMAL ORAL DIET, VIA A BOTTLE FEED, OR TUBE FED AND SPECIFIC FORMULAS ARE AVAILABLE.

How the Diet Works

There is much research in this area! The diet appears to "mimic starvation" by using fat as an alternative fuel source for the body, producing ketones. These ketones and the associated biochemical changes in the brain can have an anti-convulsive effect.

The "Holy Grail" of the ketogenic diet is for a patient to be initiated on the diet, become seizure free, reduce/remove the amount of anti-epileptic medication taken, wean the diet off after a period of 2 years and STAY seizure free. This DOES happen for some, but there are also other degrees of success on the diet:

- Reduction in number of and intensity of seizures
- Reduction in drugs and their subsequent side effects
- Increased alertness
- Improvement in behavioural problems
- Improvement in learning ability
- A BETTER QUALITY OF LIFE!

> "
> THANK YOU FROM THE BOTTOM OF OUR HEARTS.. I HONESTLY CAN'T BEAR TO IMAGINE WHAT CEILI'S LIFE WOULD BE LIKE IF WE DIDN'T RECEIVE SUCH AMAZING SUPPORT FROM YOU ALL.

Fears and Misconceptions

Arguments against using the diet usually consist of the following:

"The diet is difficult"

It depends what you mean by "difficult" – it's difficult to watch your child seize. It's difficult to watch your child in a drugged up haze. It's difficult to feel that you've "lost" the child you once had to epilepsy.

Compared to these, spending time in the kitchen, actively involved in your child's care is a piece of cake. We don't want to belittle the amount of effort needed to calculate or administer the diet – Initially you can feel like you're never out of the kitchen and it can be a daunting prospect, but we just want to put this effort in context.

Also for adults that have no quality of life, who have no social life, who can't work or drive and suffer with terrible side effects of their medication and seizures – is it really more difficult to change some of the things you eat? If it means that you have less or no seizures and a better quality of life with more choice and freedom – it is certainly worth a trial of 3 months.

> **"THANK YOU TO ALL AT MATTHEW'S FRIENDS FOR THE WONDERFUL RESOURCES AND EVIDENCE-BASED INFORMATION YOU CONTINUE TO PROVIDE FOR ALL IN NEED OF BOTH."** *DIETITIAN*

"It is unpalatable"

ALL forms of these dietary therapies are high fat, adequate protein and low in carbohydrate and in the early days of the diet the above was true – cups of oil had to be drunk and spoonfuls of butter needed to be eaten – that is NOT the case anymore.

As much as possible we work from the usual meals made at home although often we do have to change some of the ingredients to make the meal more 'ketogenic'. There are a lot of good ketogenic recipes available now and your dietitian can also help with this.

Visit the Matthew's Friends website for more recipes and we also have our recipe development kitchen producing tried and tested recipes that can be downloaded freely. Some can also be viewed on our YouTube KetoKitchen channel.

There are also many recipes available from the manufacturing companies who make foods suitable for the Ketogenic Diet and your dietitian can guide you to those appropriate for your child (or for yourself). Please make sure you work with your dietitian to adapt the recipes for your own dietetic prescription.

Visit Matthew's Friends #KetoKitchen YouTube channel for Ketogenic recipe demonstrations and tutorials!

The Ketogenic Diet for Epilepsy continued...

"It Won't Work for Everyone"

That is true – sadly the diet doesn't work for everyone, but it does have a good success rate for drug resistant epilepsies, as good as any new anti-epileptic drug that is currently on the market and remember, the drugs don't work for everyone, VNS won't work for everyone and surgery is not always an option for a patient. If the first two appropriate medications fail to control the epilepsy the chance of a 3rd working is reduced to 1%, whereas at least 50% of people who try a ketogenic diet will have a 50% or greater reduction in their seizures and we can usually tell within 3 months whether a ketogenic dietary therapy is going to be helpful or not.

"The positive effects may not last"

You may be told that "only rarely do the effects last more than 12 months" – many can testify that this is often not the case, and if things do go downhill then the diet may need fine tuning and your dietitian will offer expert advice on this as you go along.

Breakthrough seizures can be treated by changing the ratio, the calories, the timing/size of meals/snacks, changing the diet format as well as drug weaning.

"The diet won't work for adults"

There is published evidence stretching back to the 1930's and recent international experience showing that diet manipulation can have an impact on seizures and associated symptoms in adults. It is suggested that:

Approximately 40-50% of adults on supervised ketogenic diet therapy will achieve a 50% reduction in seizures; some benefiting more or less than this.

Other less quantifiable benefits commonly reported are:

- An improvement in energy levels and general 'zest for life'
- A shorter hangover time after seizures
- An improved clarity of thought and ability to make decisions
- A feeling of gaining some control over life that, in time, leads to improved mental health

Please note that any type of Ketogenic Dietary Therapy should only be undertaken with strict medical supervision by an experienced team.

Please note:

As development of these dietary therapies are continuously being updated and new information and research being carried out, please visit our website or contact our office to receive further and more detailed information on these types of therapies. This booklet offers a brief guide to Ketogenic Dietary Therapies and the work that Matthew's Friends carries out.

> **MATTHEW'S FRIENDS NOT ONLY CHANGED OUR WHOLE WORLD, BUT MOST OF ALL, SAVED PARYS' LIFE.**

A Word from the Chair of our Medical Board:

Professor J Helen Cross OBE,
MB ChB, PhD, FRCP, FRCPCH
The Prince of Wales's Chair of Childhood Epilepsy
UCL-Great Ormond Street Institute of Child Health, Great Ormond Street Hospital for Children NHS Foundation Trust, London & Young Epilepsy, Lingfield, UK.

Epilepsy affects about 1% of all children. The majority ultimately become seizure-free either through spontaneous remission or on medication and have a good prognosis with regard to seizure control and learning outcome.

In 25% of affected children however, seizures remain resistant to medication and have a high association with disability, learning and behaviour problems. This has a major impact on their lives as well as those of their families.

The ketogenic diet, a high fat diet designed to mimic starvation, has been used for the treatment of epilepsy for almost one hundred years. Although initially used widely, it became less popular with the introduction of anti-epileptic drugs.

However, with the increasing awareness that medication does not work in all cases or is not without possible side effects, use of the diet has again become prominent. Many children with seizures resistant to medication have been shown to benefit from a dietary treatment.

The diet originally used was the 'Classical' diet, where the primary fat source is long chain triglycerides (LCT) and the diet is calculated on the basis of fat to carbohydrate ratio.

Later the medium chain triglyceride (MCT) diet was developed in an attempt to ease implementation and improve tolerability. Over time, less strict regimes such as the Modified Atkins and Low Glycaemic index diets have been shown to be useful in certain circumstances and these specifically may prove to be useful in older children as well as adults.

Evidence from medical studies suggest that the ketogenic diet is effective with improvement seen in up to 60% of a drug resistant population, independent of seizure type or age of child. Only one study to date has compared the two ways of giving the diet and shown no difference. Side effects appear minimal although children require monitoring for growth and for the possible development of renal stones.

Despite its apparent efficacy however, the diet is perceived to be labour intensive and requires considerable dietetic support. Resources and expertise to implement the diet around the UK consequently remain limited.

> **KETO REALLY HAS BEEN MIKEY'S MIRACLE. IF IT WASN'T FOR MATTHEW'S FRIENDS I WOULDN'T HAVE KNOWN ABOUT KETO AND TO FIGHT FOR IT. THANK YOU ALL SO VERY MUCH.**

MATTHEW'S
FRIENDSCLINICS
KETOGENIC DIETARY THERAPIES

It has been a great honour to be involved with Matthew's Friends from its inception. As Chair of the Medical Board I have seen the organisation grow over time, and their contribution to the availability of information and services provided has been invaluable. The professionals involved are all dedicated to furthering availability of the diet where appropriate.

More recently I have been supporting the Matthew's Friends Clinics now running at Young Epilepsy, increasing the availability of the diet to children and adults where supported by their medical team.

We however are only too aware of the many questions that remain unanswered with regard to its application and the team continues to support research and education globally, including the organisation of the Global Conference on Dietary Therapies for Neurological Disease held every two years.

Matthew's Friends continues to support individuals at all levels, families and professional alike, and I remain privileged to support them.

Adults with epilepsy can benefit too!

Sadly, ketogenic diet therapy is rarely offered as an option to adults with drug resistant epilepsy even though all other treatment options having been explored and left wanting!

The first study of the ketogenic diet in adults was published in 1930 but despite positive results it was almost 70 years before another study reported similar findings. Since the year 2000, around fifteen further studies have been published using a Classical ketogenic diet or the more liberal Modified Atkins Diet to treat adults with drug resistant seizures.

Most of the studies have been small, with just 4-30 adults with only one looking at over 100 cases. Reviews of the combined data from the trials (meta-analyses) suggest that ketogenic therapy may be effective in reducing seizures in almost half the adults; comparable with the efficacy in children.

A recently published randomised controlled trial (the standard of trial most likely to influence medical practices), from Iran reported that 35% of the adults randomised to the Modified Atkins Diet gained a greater than 50% reduction in seizure frequency at the 2-month evaluation point.

Despite the numbers being small and the duration short, this randomised trial strengthens the evidence base endorsing the value of ketogenic therapy in reducing seizure frequency in adults with drug resistant epilepsy.

However, it is not just a change frequency of seizures that adults report, ketogenic diet therapy may deliver improvements in concentration, energy levels and significantly reduce recovery time. These effects alone can make such a difference to the quality of day to day life. Below are some comments from our patients who were treated at the Matthew's Friends Clinics;

> “
> *I am much more alert and energetic and no longer depressed.*

> “
> *The severity of the seizures became less and allowed me to wean off Clobazam. I now have much greater concentration and my energy levels have vastly improved.*

> “
> *I went from weekly/daily seizures to one every three months and now when I do have a tonic clonic seizure, recovery is like switching the light back on.*

> “
> I AM MUCH MORE ALERT AND ENERGETIC AND NO LONGER DEPRESSED.

Yet, adults seeking advice from their neurology teams have readily been told that ketogenic therapy is “too complex”, “unpleasant”, “unhealthy”, and “only effective in children” etc.

This has been due to a lack of experience and knowledge of the practicalities of modern day ketogenic therapy in the adult neurology and dietetic sector and little NHS funded time. However, this is now slowly changing in the UK. There is increasing interest from adult neurology teams and plans are being developed to conduct a multi-centre evaluation of ketogenic diet therapy in adults.

As adults, we are quite ready to manipulate our diets to manage diabetes, weight issues, food allergies, bowel disorders and to optimise body composition for sport, so why should it be so much more difficult for us to consider the potential impact of diet change on the course of our epilepsy?

Just a three month trial is generally sufficient to indicate whether the impact on quality of life makes ketogenic therapy worth pursuing longer term. It's time that more adults are supported to trial the ketogenic option.

Use of Ketogenic Therapy beyond epilepsy:

Currently ketogenic dietary therapy is creating immense interest in neurological research for its potential to impact on a range of neurological conditions such as: brain tumours, Alzheimer's disease, Parkinson's disease, brain injury and stroke etc.

Much of this research is still lab based, with relatively small amounts of published clinical case data, but this is an expanding field.

Ketogenic Dietary Therapy is also being studied in the areas of Diabetes, Migraine, Autism, depression, Lipedema and other lymphatic and fat disorders.

Here in the UK we are working closely with brain tumour patients, the Astro Brain Tumour Fund and the neuro oncology team at Charing Cross hospital to explore the potential of ketogenic diet therapy to:

1. Complement and enhance the effectiveness of radiotherapy and chemotherapy in those with brain tumours.
2. Provide symptomatic benefits such as a reduction in fatigue and improved control of tumour associated seizures.

A clinical trial is currently in the planning stages.

Neuro-Metabolic Disorders:

Ketogenic Dietary Therapies is also the treatment of choice for Glut 1 Deficiency, which is a rare genetic condition that affects brain metabolism as well as Pyruvate Dehydrogenase Deficiency (PDH) which is one of the most common neurodegenerative disorders associated with abnormal mitochondrial metabolism.

More details on both these conditions can be found on our website or by contacting our offices.

Please note: References for studies are available from us should you require them.

> YOUR PAGE HAS BEEN SO HELPFUL WITH IDEAS AND RECIPES FOR MY BOY AND HIS DIET. WHICH IS AMAZING AND WORKS FOR HIM SO WELL.

> HANNAH'S BEEN ON THE DIET NOW A FULL YEAR IT'S THE BEST DECISION WE'VE MADE FOR HER. SHE'S DEVELOPED IN ALL AREAS BOTH PHYSICALLY AND MENTALLY, SHE HAS LOTS MORE ENERGY AND EVEN SLEEPS BETTER. SHE WAS UNDERWEIGHT BUT IS NOW THRIVING AT A VERY HEALTHY WEIGHT.

> KEEP DOING WHAT YOU'RE DOING. THANK YOU FOR THE SUPPORT AND AWARENESS FOR PEOPLE ON THE KETOGENIC DIET. MY SON HAS GLUT 1 DEFICIENCY AND MATTHEW'S FRIENDS HAS BEEN GREAT.

Where Does Your Money Go?

Matthew's Friends Clinics/Research Projects/NHS Services

For all those areas in the UK where there is no local ketogenic dietary service/ long waiting lists, referrals can be made to our MF Clinics, where we can provide Ketogenic Dietary Therapy for both children (over the age of 1 year) and adults. More information can be found at www.mfclinics.com.

Our intention is that no-one should ever be denied these therapies in the UK because of a lack of service.

We provide funding for clinical research specific to Ketogenic Therapies.

We also provide funding for NHS Ketogenic Dietetic posts, where appropriate.

Support line number

This Support-line is available 365 days a year. It is a Matthew's Friends mobile phone number. If you do not get answered straight away, then leave a message, with your name and telephone number and we will get back to you as soon as possible, or you can text your details through to us.

Matthew's Friends Website www.matthewsfriends.org

We provide a comprehensive website with all the latest information on what is going on in the Ketogenic world. Professional world experts feed into our site in order to keep you updated. Our site is monitored carefully to make sure that all the information we provide is correct and credible. We are totally dedicated to bringing you information on all Ketogenic Dietary Therapies.

Ketogenic Starter Packs/ Literature/Resources FREELY AVAILABLE

We provide MF Ketogenic Starter Packs which are freely available to all families and patients on a medically supervised diet within the UK and Ireland.

We also supply various ketogenic resources which are available through our website shop. These can vary and are constantly being updated as new products and items become available.

Our literature is also regularly reviewed and updated by our medical board to ensure the quality of information that we provide. Refer to our website Shop for further details.

> I ATTENDED KETOCOLLEGE IN JUNE 2018. IT WAS THE BEST COURSE I'VE BEEN TO – I'VE BEEN QUALIFIED FOR 29 YEARS! I COULDN'T WAIT TO GET STARTED WITH THE DIET. YOUR WEBSITE IS INVALUABLE AND THE YOU TUBE CHANNEL IS FAB.

#KetoKitchen

We have a 'Tried and Tested' Ketogenic recipe development kitchen, where bespoke ketogenic recipes are worked on every week for families across the UK and Ireland. New recipes and tutorials are featured on our YouTube channel, MatthewsFriendsOrg.

Matthew's Friends - Around the World

We link up with other keto organisations and medical professionals from around the world and our information has been translated and used in over 20 countries at the time of writing. We have Matthew's Friends branches in Canada and New Zealand and money raised in those countries, stay in those countries, to develop their services.

Conferences and Training Meetings

We lay on regional, national and international conferences, including the bi-annual Global Symposia, for both professionals and families so as to increase the expertise within the UK and globally. We network to achieve this, together with our medical board and other global experts and organisations in this field.

Matthew's Friends KetoCollege is our annual training programme, where we provide a full CPD training course for professionals wanting to work in the medical ketogenic therapy field.

Matthew's Friends KetoCollege®

This course is led by some of the most experienced professionals currently working in ketogenic therapies and we are delighted that they will be passing on their wealth of knowledge to others, which can only benefit the patients of the future.

How You Can Help Us.....

Matthew's Friends charity relies solely on the fund-raising efforts and donations of our supporters. Please do contact us and help us to help families affected by drug-resistant complex epilepsy, Glut1 as well as emerging neurological disorders and cancer types that may benefit from Ketogenic Dietary Therapies.

There are a number of ways to help, these include the following, or you may have a great idea of your own!

- Visit www.justgiving.com/matthewsfriends to donate or to set-up your own sponsorship page for any sponsored event.
- Organise a 'Purple' event around Purple Day to raise awareness of epilepsy and raise funds for Matthew's Friends, UK partners of Purple Day – 26th March every year.
- Hold a coffee morning, run a marathon, or anything in between and we will support you with sponsor forms, charity literature, running vests etc.... all you need for a successful event.
- Provide photos of your event and see them featured in our online newsletter!
- Make regular monthly/quarterly donations – these really help us to plan ahead – please contact us for a standing order form
- Attend a Matthew's Friends event – we hold a fantastic annual Ball, quiz nights and events with our Patron Tony Tobin and much more all year round – check out our website for the latest events!
- Do your regular online shopping via our Easyfundraising.org link and raise funds at no extra cost to you! www.easyfundraising.org.uk/causes/matthews-friends

Find us on: facebook

twitter @matthewsfriends

matthewsfriendsketogenic

For more information on how to help please contact us on
enq@matthewsfriends.org

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Meet Our Patrons.....

CELEBRITY CHEF TONY TOBIN
FOUNDING PATRON SINCE 2004

Tony is well known to viewers of the BBC's Ready Steady Cook having appeared on the show over 300 times since 1992. Tony has been with Matthew's Friends from the very beginning in 2004 and we are very proud to be 'his' charity. Tony has worked with us to try and raise awareness as well as raising funds for us with his marathons, gourmet evenings and supporting our Rainbow Balls. He really is a very 'hands on' patron and a lovely guy to work with.

Message from Tony....

"When Emma wrote to me, asking me to join Matthew's Friends as their patron, I, like most people, had never heard of the Ketogenic Diet. Ignorantly, I presumed that all children suffering from Epilepsy were given drugs that stopped it. I had no idea of the cocktail of drugs some of these children have to take on a daily basis. I also didn't know that in some cases the drugs actually make their condition worse not better. To then read that a diet can replace or reduce drugs and work, is remarkable. Especially when some of those children that go on the diet can become completely seizure free and go on to lead normal lives.

After reading Matthew's story there was no doubt in my mind that I wanted to help. Matthew's Friends is an amazing charity and if by raising awareness of the Ketogenic Diet we can help other children like Matthew, then I am more than willing to do whatever I can to be part of it.

Since joining the charity in 2004 I have watched it grow at a phenomenal rate, and had contact with families from all over the globe. The fact that adults are now starting to be treated AND we are also beginning clinical research looking at the ketogenic diet for those with Brain Cancer and other serious neurological conditions means that the charity as well as our Matthew's Friends clinic is just going to get even busier.

As a chef, the fact that this charity has a lot to do with food is obviously of great interest to me. Food has been a very positive part of my life, just like it was such a very positive part of Matthew's life and still is!

I look forward to meeting many more families in the years to come and seeing many more people benefit from these diets and have a better life."

Tony Tobin

ACTRESS AND COOKERY WRITER - FAY RIPLEY
Patron since 2013

Fay Ripley is a BAFTA nominated actress and an award-winning, best selling cookery writer having written three cookery books 'What's For Dinner', 'Fay's Family Food' and 'Fay Makes it Easy'.

This is what she has to say...

"After learning about Charlie's Story through the narration I was doing for a programme on Channel 4, I was completely blown away with how ketogenic dietary therapies can change a child's life so dramatically.

Charlie becoming seizure free because of what he was eating was just such an incredible story that I knew that I wanted to find out more, so I contacted Emma Williams and upon learning about Matthew's story and the damage that he suffered because he was denied the diet for so long, then there was no doubt in my mind that I wanted to help. As well as acting, food has always been a passion of mine and I share the belief of the charity that all those who want to try a ketogenic diet should be able to. What have you got to lose?

I am delighted to be a Patron for this amazing charity that has gone from strength to strength and does so much to support families, patients and professionals in using these dietary therapies."

Fay Ripley

Our Patrons with Matthew and his Family

The boy behind the charity meet Matthew Williams

Matthew Williams was born on the 8th September 1994 and at the age of nine months old he had his first seizure, this seizure lasted for about twenty minutes and was the start of a very long and traumatic journey for my family.

At one stage Matthew was having prolonged bouts of status epilepticus and many nights I spent in hospital with him in intensive care not knowing whether he was going to live or die.

I watched my son seize for hours in some cases and the future looked extremely bleak. Matthew was put on a lot of medication and the side effects from these started to become unbearable.

In the beginning when your child has a seizure, you hold them and pray that they are going to be ok, that they are not going to die, but for us it got so bad that when Matthew had yet another prolonged attack, I would hold him and pray that he would die as I just couldn't bear to see him suffer so much – then of course the guilt takes hold of you for even thinking such a thing.

The more medication Matthew was put on, the worse his seizures and quality of life became.

Matthew aged 6 weeks

> “
> MATTHEW WAS PUT ON A LOT OF MEDICATION AND THE SIDE EFFECTS FROM THESE STARTED TO BECOME UNBEARABLE.

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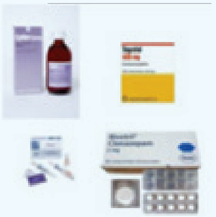
Matt's meds and side effects

- Prolonged Tonic-Clonics



- Prolonged Tonic-Clonics
- Myoclonic Jerks
- Status Epilepticus
- Behavioural Problems

- Prolonged Tonic-Clonics
- Myoclonic Jerks
- Status Epilepticus
- Complex Partials
- Intensive Care Visits
- Behavioural Problems
- Sleep problems

AND MORE

- Prolonged Tonic-Clonics
- Absences
- Myoclonic Jerks
- Status Epilepticus
- Complex Partials
- Intensive Care Visits
- Behavioural Problems
- Sleep problems

- Prolonged Tonic-Clonics
- Drop Attacks
- Absences
- Myoclonic Jerks
- Status Epilepticus
- Complex Partials
- Intensive Care Visits
- Behavioural Problems
- Never Slept
- Rash
- Screaming Constantly

- Tonic-Clonics
- Absences
- Drop Attacks
- Myoclonic Jerks
- Reduced Status Attacks
- Complex Partials
- Hospital Stays
- Behavioural Problems
- Sleep problems

Matthew aged 8 with Emma and his sister Alice aged 6

I first found out about the Ketogenic Diet when Matthew was about 2 years old, but when I asked Matthew's then Paediatric Neurologist about it, she said that the diet did not work, that it was unpalatable, the children were sick through it and medication was by far the better option and I was made to feel guilty for suggesting the diet being told "don't you think your son is suffering enough without putting him through this diet as well".

I believed her and did what I was told like a good parent. I carried on with the merry-go-round of different medications, but nothing seemed to stop Matthew's seizures and if anything they were making the situation a whole lot worse. Matthew was also assessed for brain surgery, but by this time he had so much scarring and damage to his brain because of all the seizures, that there was no way that they could carry out any kind of brain surgery that would be of any benefit to him.

The drug merry-go-round went on for nearly six years and periodically in that time, I kept on asking for the diet and kept being refused. By this time, the film 'First Do No Harm' had been made highlighting the Ketogenic Diet, but when I questioned the doctors, again, I was told it was 'Hollywood hype' and the diet really didn't work that well and that this film did not give the details of all the terrible side effects that there were with the Ketogenic Diet and once again I was told that drugs were the best option.

However, Matthew was having terrible seizures every day, numerous tonic clonic seizures, drop attacks, absences as well as myoclonic jerks so powerful that they would knock him off his feet. The doctors said that IF he made it to the age of 12 then he would probably need to be in a residential placement as we would not be able to deal with him living at home anymore.

The family fell apart and I was now a single mother of not only a severely disabled little boy but also his younger sister Alice, whose life was also a complete misery as everything had to revolve around her brother.

When Matthew was 7 years old, on a yearly routine appointment with the same neurologist, I insisted that I wanted the diet because basically there was nothing else left to try. It was a choice of going through the same drugs he had tried before but in different combinations and more of them OR get him onto the ketogenic diet. There was no choice as far as I was concerned. I had to tick that box. The side effects of the medications were awful and his quality of life was so poor already that it really could not have got any worse for any of us.

Thankfully, Professor Helen Cross OBE and Dr Elizabeth Neal RD had just started their Ketogenic Diet Clinical trial at Great Ormond Street Hospital, so we were referred over to see them and Matthew was accepted to take part and within 2 weeks of starting the classical Ketogenic Diet. Matthew's seizures had reduced by 90% and within eight months of starting the diet he was off ALL medication!

His quality of life improved dramatically, no longer were there terrible side effects from the medication, no longer did Matthew scream all day, no longer was Matthew aggressive to anyone around him by biting, hitting and pinching, no longer did Matthew try to knock over furniture in the house and generally disrupt the whole family. He was calmer, happier, more relaxed, sleeping and turned into a very loving little boy.

I had finally got back what was left of my son and my daughter could finally have some kind of sibling relationship with her older brother. It was a joy to watch.

> MATTHEW'S FRIENDS HAVE ALWAYS BEEN THERE FOR ME, I HAVE MADE SOME GREAT, LIFELONG FRIENDS WHO UNDERSTAND WHAT I AM GOING THROUGH AND SUPPORT ME ALL THE WAY... ALL BECAUSE OF THIS CHARITY. I JUST CAN'T THANK YOU ENOUGH.

Matt as a toddler

The fear that I was made to feel over the side effects of the diet were totally unfounded. Matthew experienced NO horrendous side affects to the diet whatsoever, Matthew was NOT sick all the time and the food was NOT disgusting and unpalatable.

In fact in some cases, it was more difficult for Matthew's sister Alice, as there was Matthew eating a nice Keto blueberry muffin and a banana milkshake for breakfast, whereas his sister was only allowed a bowl of cereal or some toast!

Matthew was on one version or another of the diet for nearly six years and did just fine, the only reason he was kept on it for so long was because I was too scared to wean him off! During this time, we also discovered that Matthew had Dravet Syndrome, a catastrophic epilepsy syndrome.

It was with this diagnosis that we understood why some of the drugs had been so horrendous for him, as they were not suitable to be used with Dravet Syndrome, no wonder Matthew was so unhappy and suffered so much with life threatening seizures. We also know now that Dravet can respond very well to ketogenic therapy and that was the treatment he had needed but had been denied for so long. Instead he had been put on a cocktail of drugs that were not suitable for his condition.

He was eventually weaned off the MCT ketogenic diet in August 2007 and the seizure numbers never increased from what they were when he was on the diet.

The only small issue we had was that they increased in length of time slightly. With that in mind, I discussed things fully with Professor Cross and we decided to try him back on a very small dose of Epilim, which is a drug recommended for Dravet.

> HE CAN EAT WHATEVER HE WANTS, ALTHOUGH I AM CAREFUL WITH HOW MUCH SUGAR HE HAS – WHICH IS NO BAD THING IN ANY EVENT.

Although at the time it felt like I was taking a step backwards, understanding his diagnosis made it clear that he did need something to keep things under control to give him the best quality of life possible, be it drug or diet.

We decided that as he had been on diet for 6 years, we would give him a 'keto break' for a year and try him on a little Epilim and then review after a year. Matthew is still on that keto break today and he takes just a small dose of Epilim twice a day and that was enough to bring the seizures he had left back down in length of time to about 40 seconds.

This we could deal with and it didn't affect his quality of life. He has no terrible side effects and for Matthew, this is HIS therapeutic dose of medication. If ever things changed and went downhill, then I would have no hesitation in putting him back onto ketogenic therapy and weaning off the medication. Monotherapy is always my goal for Matthew.

He can eat whatever he wants now, although I am careful with how much sugar he has – which is no bad thing in any event.

I was outraged that Matthew had been denied this treatment for so long when it obviously DID work.

I felt that I had been given a lot of false information about this treatment and although I believed (and still do) that we were in one of the best hospitals in the world, unfortunately I was in front of a doctor that did not believe in the diet and who was happier to give out a vast quantity of drugs without realising what it was like to actually live with a child that suffered with such terrible side effects to those medications as well as horrendous seizures. So with the intention of not wanting any other parent to go through the same as we had been through, I launched Matthew's Friends in 2004 to make sure that the correct information was available for ALL regarding ketogenic therapies.

We have the right to make an 'informed' choice. The diet won't work for everyone and some will find it easier than others to do, but everyone has the right to a choice and to know that support is there for them if they should need it.

Matt aged 18 with his sister Alice and me!

> I HAD FINALLY GOT BACK WHAT WAS LEFT OF MY SON AND MY DAUGHTER COULD FINALLY HAVE SOME KIND OF SIBLING RELATIONSHIP WITH HER OLDER BROTHER

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Update:
Matthew January 2019:

Matthew is now 24 and he is still living happily at home with me. We have been through the pain barrier that is transition into adult services and we have direct payments which means I can employ carers to look after him when I am at work or away.

For us, a residential placement is not an option and we have organised a schedule for him where he does something he loves every day and he has a great quality of life.

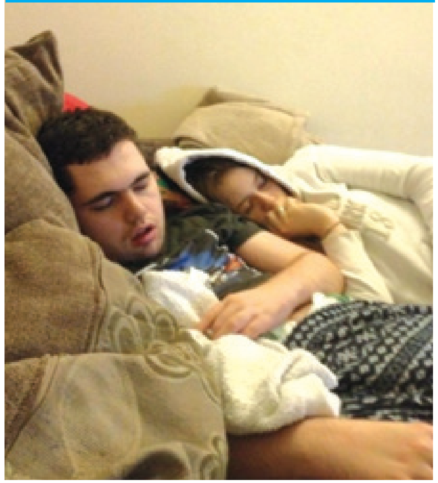
He is profoundly disabled and always will be, we always knew that, especially when he was diagnosed with Dravet Syndrome, but I wanted him happy and not suffering – it has always been about his quality of life first and foremost and he is very happy young man, surrounded by the people who love and care for him and pander to his every need and yes, he is a bit of a 'mummy's boy' and I am quite happy for that to continue.

He and his sister have a lovely relationship and she is now at Medical School training to be a doctor. He misses her dreadfully when she is away but when she returns home normal service is resumed.

I am so very proud of both of them and what they have achieved and what they inspire. It is a true honour and blessing to be their mother.

Matt with Alice, Emma and Professor Helen Cross OBE when Matthew was a mascot for the England Rugby Team in May 2015.

Brother and sister post Sunday lunch snooze together!



Matthew celebrating being 21!

Matthew Swimming – his favourite activity

Matt at a recent Matthew's Friends Conference with Emma and Alice.

Matthew's Friends charity:

I am very proud of the work we have done so far in making these therapies more widely available for all those who should need them.

I am extremely proud of the team that work tirelessly with me to ensure that we support our families and our professionals so that the very best hope and opportunity is given to all those using dietary therapies. We KNOW that by the time families get to us they have already been through hell and back.

I am also extremely proud of all the families that I have worked with over the years – you are truly awesome and I look forward to all the new "Matthew's Friends" families that I will meet over the coming years.

I LOVE the ketogenic diet and I LOVE all the stories and emails that are sent to me everyday telling me about your loved ones and how well they are doing.

Please keep them coming and let us share our stories with others, give them hope, inspiration and most of all, our support. For those of you who are unsure, feel free to call me, email me and we will give you as much information as we can. We will help you every step of the ketogenic way. After all, the diet is ALL we do.

I really hope ketogenic therapy helps you or your loved one the same way as it helped Matthew and my family and I look forward to sharing YOUR story.

With very best wishes.

Emma Williams MBE
Mum to Matthew
& Founder/CEO – MF Charity
Director – MF Clinics

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How to contact us:

MATTHEWS FRIENDS
Ketogenic Dietary Therapies
Information • Training • Research • Support
Registered Charity No. 1108016

Post:
Matthew’s Friends
St. Piers Lane
Lingfield
Surrey RH7 6PW

Telephone (Office):
01342 836571

Fax (Office):
01342 837792

Support-line Number:
0788 4054811

Website address:
www.matthewsfriends.org

General E-mail:
enq@matthewsfriends.org

matthewsfriends
@matthewsfriends
matthewsfriendsketogenic

MF
MATTHEW’S
FRIENDSCLINICS
KETOGENIC DIETARY THERAPIES

Post:
Matthew’s Friends Clinics Ltd
St. Piers Lane
Lingfield
Surrey RH7 6PW

Telephone (Office):
01342 836571

Fax (Office):
01342 837792

Support-line Number:
0788 4054811

Website address:
www.mfclinics.com

Email
info@mfclinics.com

Matthew’s Friends
Keto College®

General E-mail:
Ketocollege@mfclinics.com

Website address:
www.mfclinics.com/keto-college