I AM GOING ON A KETOGENIC DIET

What is a Ketogenic Diet and why do I need to go on it?

Written by Emma Williams MBE
CEO/Founder Matthew’s Friends
What is a ketogenic diet?

This treatment could be a way of helping to try and make your seizures better or possibly stop them altogether. It is a very special diet that uses the food you eat to try and stop the seizures you have, instead of having to have another medicine.

Foods like...

- Cheese
- Bacon
- Strawberries
- Eggs
- Chicken
- Cream
It is VERY important that we make sure our very clever brain gets enough fuel and there are two types of fuel that our very clever brain can use:

1. The first one is called GLUCOSE which we get from things like bread, rice, pasta, cereals, fruit and vegetables (these are called ‘carbohydrates’)

2. The second one is called KETONES which we get from things like butter, cream, cheese and oil (these are called ‘fats’)

Our very clever brain picks Glucose first for its fuel as usually there is plenty of it to use, but if we don’t have enough Glucose in our body to fuel our brain, then our very clever brain will ‘switch over’ and start using Ketones from any fat that we have in our body. We don’t feel it switch over it is just something that happens.

It is these ketones that seem to stop or reduce seizures in some children, so this diet is a way of making your very clever brain use ketones NOT glucose. You just have to eat the foods which help your body use fat for energy so that it can make the ketones.
How soon will I know if my ketogenic diet is working?

Some children improve within a couple of weeks while others can take more time. We usually say you should try the diet for at least 3 months to see if it helps you. If it does make you feel better and have fewer seizures then you will stay on the diet.

How will I feel on my ketogenic diet?

Not everyone feels the same on the diet. Most children feel well, but in the beginning you may feel a little sleepy and a bit miserable, this does go away after a few days. Some children will become even more active than usual and have lots more energy.

Will I feel hungry?

Although the meals will look smaller than normal, you should not be hungry. Foods that make ketones make you feel full quickly, so you don’t need as much of them as you are used to having. They will still taste delicious though.

Do I have to go into Hospital?

Some children stay in hospital when they start the diet and others may start the diet at home – it depends on how your Keto Team like to do things. Both ways are fine.
Why do I have to see a Doctor and Dietitian (Keto Team) for my ketogenic diet?

This is a very special diet that has to be worked out for just for you – Nobody else is allowed YOUR diet.

You should be used to seeing your doctor about your medicine anyway, only now you will be seeing your doctor about your ketogenic diet too. Your doctor is there to look after you and try to make sure that you keep well.

A Dietitian will work out your ketogenic diet for you to make sure that your very clever brain gets all the fuel (Ketones) that it needs. She will help to make sure you have delicious food to eat and can create some special recipes just for you. She will make sure that she includes as many of your favourite foods as she can.

When you go to see your dietitian...

When you go to see your dietitian, she will be checking your weight and height and plotting them on a chart – just to make sure that everything is going well.

Sometimes you may need to have some blood tests done. If you don’t like blood tests, then don’t worry, ask one of the nurses to put on some ‘magic cream’ before you have the test and you won’t feel a thing!
Can I eat snacks on the ketogenic diet?

Snacks can be included in your ketogenic diet, but your dietitian will also have to work these out for you in the same way as she has to work out your meals. You can only eat foods that are allowed on your diet. There are lots of lovely things that can be made for you that are delicious to eat and your family can find the recipes on the Matthew’s Friends website such as...

Chocolate Brownies  Pizza  Chocolate Fudge

Celebration Cakes  Pasta Carbonara  Pork Stroganoff

Can I still do all the things that I like to do now?

Yes, of course you can, you just need to make sure you have your special food (diet) with you.

What if I make a mistake and eat something that is not on my diet?

This may mean that the diet will not work as well as it should for a while and you could have more seizures - so try to be as careful as you can and get back on track as quickly as you can.
Will I still need to take my medicine when I am on this diet?

At the start of the diet then yes, you will probably have to take your medicine as well, just until we know whether the diet is going to help you or not.

If the diet helps you then it is quite usual for your doctor to start cutting down the amount of medicine you have to take each day.

**BUT REMEMBER THE GOLDEN RULE...**

"Don’t stop your medicine or start reducing the amount you take unless your Doctor tells you that it is safe to do so."

If my ketogenic diet works, do I have to be on this diet forever?

It depends on the type of epilepsy you have OR if you have a specific condition that means you have to be on the diet for life. Your dietitian and doctor will give you guidance on how long YOU may need to stay on the diet. However, in most instances, it is advised you stay on the diet for about 2 years.

Will the ketogenic diet make me ill?

No, it shouldn’t make you ill. In the beginning you may feel a little sick as you get used to it, but this usually passes quite quickly, and it does not happen for everyone. Your Dietitian and Doctor are there to look after you together with your family and they will make sure you keep as well and happy as possible.
Is the ketogenic diet difficult?

The diet may seem very different in the beginning and will take some getting used to. It may also be very confusing to start with as well. However, with time it will become a lot easier and you will get used to it. The dietitian will support and help you and your family and Matthew’s Friends will also be here to help.

What do I tell my friends about my diet?

Be honest with them and tell them all about your special diet. You could show them this booklet if you want to – it will help explain things. Ask them to help you by making sure that you don’t accidentally eat something you shouldn’t!

Will my food look very different from what my friends have?

Yes, it can look different, but try not to worry about it. Remember not everyone likes the same foods whether they are on a special diet or not and you will still have nice food on this diet.

Will I become fat?

No, you shouldn’t get fat. You only become fat if you eat too much food and don’t exercise enough. Your dietitian will make sure that you get the right amount of food that YOU need for YOUR ketogenic diet.

Is the ketogenic diet bad for my heart?

The diet is high in fat but this fat is changed to ketones and used up by our very clever brain to give the body energy. So this means that there is not lots of fat left hanging around in our bodies that would normally be bad for our heart. Your heart should stay as strong as it is now.
Do I have to take anything else on my Ketogenic diet?

Yes. You will have to take some Vitamins and your dietitian will give you these. It is very important that you take them with your diet every day as these will also help to keep you healthy and strong.

Our very clever Brain is busy using up all the fat.

Exercise is good to keep your Heart healthy and strong too.

What else do I have to do?

You will normally have to test your ketones every day at home – this is very easy to do. After you have been to the toilet, you just dip a special stick (like the one in the picture below) into your urine and then the stick will change colour and go darker. The darker the stick goes, the more ketones you have – which is good. Sometimes ketones are checked by taking a pin prick of blood from your finger. This is over very quickly and is not painful, but if you really hate the idea of having your finger pricked then we can use the Urine dip stick.
Remind me of what the ketogenic diet can do for me?

You may not have to take as much medicine (or any at all) and many children feel better on the diet. Your seizures may improve, become less frequent and could even stop altogether.

You could have more energy to play, have fun and enjoy your life without lots of seizures.

Who are Matthew’s Friends?

Matthew is a boy that went on the ketogenic diet, just like you’re going to. He used to have hundreds of seizures every week but the ketogenic diet stopped nearly all of them. His mummy decided to start a charity called ‘Matthew’s Friends’ in order to help other families that wanted to use the Ketogenic diet.

Today, Matthew’s Friends help families and children all over the world using ketogenic diets, just like they are here to help you and your family.

A Message from Matthew

THE BOY BEHIND THE CHARITY

I was 7 years old when I went on the ketogenic diet and it stopped nearly all of my seizures. I am not on the diet anymore as I don’t need to be. This diet was the best thing to have happened to me. I really, really hope that the Ketogenic Diet helps you too.

Good Luck, from your Friend, Matthew. Xx

When you first look at a ketogenic diet as a parent/carer, it can be really daunting. To try to explain it to your child or their siblings can be equally as daunting. I certainly experienced that when trying to make Matthew understand why his dinner looked so much smaller than it used to be and when taking a very confused looking Alice into the bathroom to eat some chocolate where Matthew couldn’t see us!

Over the years, we have reprinted this booklet several times and had great feedback. Apparently it is particularly useful for schools, respite centres and extended family members!

However you use it, we hope that it helps you and your family. We all wish you the best of luck with your ketogenic diet and remember that we are always here to help and support and we would love to hear about your ketogenic experience.

Very best wishes,
Emma Williams MBE – Founder/CEO

Emma with Matthew and his sister, Alice.
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