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## **School/Respite Centre Information Sheet 2**

### **MANAGING A DIET IN SCHOOL**

#### **A DAUNTING PROSPECT?**

When presented with a child who is on the Ketogenic Diet or about to go on the Ketogenic Diet, it is fully understandable that this may be rather worrying for all concerned. From the parent's point of view, they will not be able to monitor everything that is going on at school and from a school's point of view, with resources and time already very tight, having to manage a child on a very specialised diet can be somewhat overwhelming. However, this need not be the case. The most important thing to make a Ketogenic Diet work at school is good communication between parent and the school. The Diet needs to be treated with as much respect as giving a child medication or a child with a peanut allergy. Fluctuations on this diet or even the tiniest of cheats can affect a child's seizure control.

#### **WHAT IS THE KETOGENIC DIET?**

This is a MEDICAL dietary treatment for epilepsy and as such, must be calculated for each individual child by a qualified dietitian. It is a high fat, low carbohydrate, adequate protein and vitamin supplemented diet that is also calorie restricted. In many children it can reduce seizures dramatically and in some, stop seizures completely. There is a dramatic resurgence of interest in the diet now as drugs do not work for everyone and the Great Ormond Street Clinical Trial published in May 2008 has demonstrated that this treatment should be considered by all those who are resistant to medication.

The Ketogenic Diet mimics starvation. During starvation, the body uses stored body fat for energy instead of stored glucose (which we get from carbohydrates and sugars.) When this fat is metabolised the residue is referred to as ketones and it is

the body being in this ketotic state or the ketones produced that we think has an anticonvulsant effect, although the real reason why this diet works is still unknown. Our bodies are obviously used to and find it easier to use glucose for energy so giving one sweet or a tiny piece of bread to a child can reduce ketones and may cause additional seizures – so the diet has to be very strict.

For more information on the Ketogenic Diet please visit our website or read our Schools Information Sheet 1 – Ketogenic Diet – A Brief Outline.

### **WHAT HAPPENS WHEN A CHILD STARTS THE KETOGENIC DIET?**

The diet may take some getting used to as this is a big change for the child's metabolism. Initially there may be issues with tolerability like nausea, vomiting and abdominal cramps, depending on which version of the diet a child receives, however these side effects can be minimal and easily overcome by adjustment of the diet. Communicate with the parents if you have ANY concerns, as they will be in regular contact with their dietitian.

Initially the most common problem can be excess ketosis and with this you may notice that the face may become red or appear flushed. The child may also become agitated or overly lethargic. If you have any concerns regarding this, a small amount of juice or another high sugar drink (10-15 mls) should be given and within 15 minutes the child should be better. If no improvement is seen then medical opinion should be sought. If you are in any doubt of this then contact the parents IMMEDIATELY who will liaise with you and communicate with the dietitian directly. If this situation persists it may be that the child needs an adjustment to the diet, but the parents should keep you fully informed.

To monitor this treatment the child will need to be weighed probably weekly, height checked monthly and urine will need to be tested morning and night by the parents to measure urinary ketones. In some cases blood ketones will be tested by finger prick. The child will have regular check-ups with the neurologist, dietitian and specialist nurse to monitor progress including blood testing.

Excess Bruising - When on the ketogenic diet, it seems that children can bruise a lot easier than when they are on a normal diet. This is a KNOWN side effect of this treatment and in some instances the slightest knock or bang can cause a nasty bruise.

## **HOW WILL THE DIET AFFECT THE DAY TO DAY ROUTINES?**

### **P.E. & GAMES**

If the child is using extra energy e.g. swimming or P.E, it may mean that extra calories are needed. The parents can send in an extra snack that can be given prior to this activity. If you notice that the child is becoming particularly tired after a PE session, or lethargic for the rest of the day, then please talk to the parents and let them know and they will be able to liaise with their dietitian to send in extra snacks to counteract this problem.

### **WHAT HAPPENS AT MEAL TIMES?**

The most important thing to remember is the child cannot eat anything that is not provided by the parents.

It's important that the child eats ALL the food that has been provided, so what you will need to do is make sure the child is supervised adequately. This means that at any food times, all food and drink that is necessary on that child's diet is eaten. This may mean that a teaching assistant has to scrape the bowl out for the remainder of the fat to be eaten. Obviously there will be occasions when the child will not finish everything and if there are any problems with the child's eating then it is a good idea to mark it down in their home/school book. If it is really proving a struggle and the child will not eat anything, then this must be communicated to the parents.

Each meal is a balance of fat, protein and carbohydrates given at regular intervals throughout the day. All food must be eaten especially if oil is left from any meal as this may well contain a high proportion of fat that is needed for that child.

Some children may have a supplemented drink as part of their meal; this must be taken with or just after the meal. It is very important that the fat part of the meal is eaten. If the child is having problems eating the whole meal, let the parents know that it may be better to supply all-in-one meals so that however much is eaten it will be in the right proportion of fat, protein and carbohydrate. If you feel that problems with eating seem to be behaviour related then please discuss this with the parents where suitable programmes of behaviour can be set up between school and home.

Most children will want to eat with the other children as usual and will be part of special occasions. With advanced warning, parents will be able to send in a special snack or a treat so the child can be included. Water is unrestricted, some low calorie squash and most low calorie fizzy drinks are okay as long as the parents have consented to their child being given them. Parents and carers will try and fit in with the daily school routine, if there is a snack time, a snack can be brought in. It may be useful to have copies of the school menus so that a Keto version of the day's

meals can be sent in where possible and re-heated if allowed. Hot keto meals can also be brought in using a flask if re-heating is not permitted.

## **WHAT ABOUT COOKERY LESSONS?**

This is a challenge, there is no doubt about that one and there are some children on the diet that become intent on cheating and will eat anything they can get their hands on (we have had a case of raw oxo cubes!) and in these cases it may be prudent to give an alternative option. The majority though, are happy to continue cooking with the other children and providing enough notice is given, may be able to make a Keto version that they can actually eat. Alternatively, children are often happy to make the same as other children and take pleasure in bringing home what they have made for their families.

Food can be used for many subjects in school, in history we can taste what the food would have been like in Victorian times, we can experience an Egyptian banquet (this has been one that has come home from school before!) and we know that this has been the case for a lot of our parents as we have received a lot of phone calls requesting help with a menu plan for an 'historic banquet!'

Using food in special needs schools seems a very popular way of teaching children. This CAN still be achieved with a child on the Ketogenic Diet, but this is where the good communication with the parents is so important. If the teacher knows that they are going to be using food as part of their lesson plan over the next few days or following week, then notes need to be sent home to the parents to see if there is some way they can incorporate a child's Ketogenic food in with what the rest of the class is doing.

## **WHAT ABOUT GOING ON TRIPS?**

There is no reason why a child on the Ketogenic Diet cannot be included in school trips, plays and other such school activities. Some trips will often involve food and this should not mean that a child cannot go. Packed lunches have to be sent in every day anyway for a ketokid. If it is a visit which includes a trip to McDonalds – this can be got round in some instances and a chat with mum or dad should be able to sort this out or ask mum to come along to 'help out' for the day!

## **WHAT ABOUT REWARDS SYSTEMS & PARTIES?**

Some schools give sweets or chocolate as a reward for good work etc but it is becoming more common with the healthy schools programme that healthy alternatives are offered instead. However those healthy alternatives can prove not so healthy for our ketokids so we suggest a small gift system such as pencils or

rubbers or age appropriate capability gifts/rewards can be used instead, as well as the usual star charts.

As for parties – again with communication to the parents Keto Party food can be sent in for the ketokid. Some parents also provide school with sugar free jellies or sugar free ice pops that can be kept and given out to the children – but again this is a plan that you can discuss with the parents. Sugar free jelly or sugar free ice pops are good to use because ALL the children can have them helping the ketokid to feel included.

## **HAPPY CHILDREN**

As we said at the beginning of this information sheet, sometimes the drugs just don't work and some children can suffer with such awful side effects that their quality of life can be seriously affected. The Ketogenic Diet could possibly offer up to a third of children a greater than 90% reduction in their seizures or complete seizure freedom. Another third will have a 50% reduction in seizures and for the final third, sadly the treatment will not work. At its best, the Ketogenic Diet can increase alertness, improve motor skills, improve cognitive skills, bring seizure freedom, reduce seizures, reduce severity of seizures, improve behaviour, decrease medication or in fact stop all medication, reduce hospital admissions, reduce time off school and improve the quality of life for the whole family.

Meals may look small in some cases and the children cannot have the same sweets that their friends may have, but the benefits that can be witnessed with this treatment can generally outweigh these concerns. A positive attitude towards the treatment is a HUGE help to the child AND their families – **YOUR SUPPORT IS VERY IMPORTANT** and you have a vital role to play in the success of this treatment.

If you notice the child becoming fed up with the treatment (and this will happen from time to time) then let the parents know and together WITH the parents, simple changes can be made that may make a huge difference to the child and hopefully help them overcome whatever negative feelings they may have on occasions. The most important thing that EVERYBODY needs to do is give a positive attitude towards this diet and lots of encouragement and praise is always welcome, especially in the beginning.

THE 2 KEYWORDS TO REMEMBER ARE:

**SUPERVISION AND COMMUNICATION**

FOR FURTHER INFORMATION:

Please visit our website at [www.matthewsfriends.org](http://www.matthewsfriends.org)

For all general enquiries and if you wish for Matthews Friends to visit your school and provide staff training/information then please contact:

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