

# PREPARING FOR & GETTING STARTED ON THE KETOGENIC DIET

## 1. Commit Yourself for at least 3 to 6 Months for Ketogenic Diet Initiation:

Three months is the time proposed to trial any form of the ketogenic diet with reductions in seizure frequency usually seen within the first 3 months. Diet initiation, food preparation, trying new food preparation techniques, product trials, fine tuning, etc, all take time to implement. You will receive support and guidance on food preparation and recipes from your dietitian during this time. Avoid planning events, travel, activities, tasks that may interfere with your ability to commit to the diet preparation and administration. It is important to ensure 100% commitment is given during this trial period to increase the chance of success and to decrease any barriers to making the diet work.

## 2. Consider Your Expectations for Success or Failure Using the Diet:

Think about this one and discuss it with your family. For some, complete seizure control, elimination of medications and improvements at school or work is success and anything less is failure. For others, they want to be off medications (or reduce them) or they want to feel better and have a better quality of life. For example, a 50% reduction in seizures for someone who is having hundreds a week may be considered success. Outcomes of using the ketogenic diet may include:

- ✓ Reduction of seizures or even seizure freedom.
- ✓ Improved quality of life.
- ✓ Reduction of medication or even medication freedom.
- ✓ Involvement in treatment either trying to help yourself or as a parent for your child's treatment, either of which can be very empowering.
- ✓ Reduction in seizure intensity & recovery time from seizures.
- ✓ Increased alertness.

Be honest with yourself as to what your expectations are. We all hope for complete seizure control, no medications and an end to the nightmare and for some, that dream **WILL** come true. For those children with **very** difficult to control epilepsy or adults with epilepsy since childhood, it may take a longer time to see the benefits, and those benefits may not include complete seizure control. Keeping a daily diary may be useful to track how you feel and any changes in symptoms or seizure frequency. Success stories can be found on the Matthew's Friends website.

### 3. Communicate With Everyone

#### Your Family

Discuss the ketogenic diet therapy with your family (siblings, grandparents, aunts, uncles included). Give them all the information you have and ask them for their support and understanding for at least the first 3 months. It is important that you have as many people on board to work **WITH** you, especially in the beginning. The more support you have, the better the chances of success. If improvements are seen and the diet is working well family members will see the results for themselves and have the understanding of how the diet worked to help. Explain to siblings that they won't be able to share their food with their brother/sister because it could make them unwell.

In the case of young children and limiting foods, family members may express sympathy or pity. No one likes to be denied anything and no one likes to deny a child. Educating family about keeping the focus on the trial period and all the possible positive outcomes will help avoid unnecessary comments or mistakes.

For further information for family members or close family friends that have questions or concerns, contact your ketogenic registered dietitian or Matthew's Friends Canada staff.

#### Your Child's School

Discuss the ketogenic diet therapy with your child's school (teachers, assistants, principal, etc) and provide them with the Matthews Friends Canada handout '**Managing the Diet in School**'. Good communication and support from parents and the school will be required to ensure the diet therapy is continued during the school day as it would at home. It is important for school staff to understand that the ketogenic diet is a medical therapy and requires the same respect as a child receiving a medication while at school or a child with a severe food allergy.

Specific changes for your child at school may include:

- ✓ Eating only foods and drinks packed from home.
- ✓ Eating all of the food provided from home and ask school staff to help 'scrape' up remaining dressings, sauces etc.
- ✓ Arranging food alternatives (rewards) or food prepared for special occasions.
- ✓ Educating classmates, parents and school staff about the ketogenic diet; telling classmates, parents & staff why your child is going on a special diet and the fact that it could really help them get better will hopefully help the other children in the class to understand why they must not share their food with their classmate.



## **Daycare or Respite Centre**

Discuss the ketogenic diet therapy with your child's care centre (caregivers, teachers, assistants, etc.) and if appropriate provide them with the Matthews Friends Canada handout '**Managing the Diet in School**'. Provide them with all the information you have. Depending on the facility and staff, food preparation may be difficult and some centres

may be hesitant to accept a child on a specialized diet. In those cases, providing prepared meals from home and education/support for staff may be beneficial. If the centre is willing to prepare food for your child, provide them with education, guidance, and support (ie recipes, handouts, a weigh scale if necessary). Take them through everything and how you to prepare foods. Use the most basic recipes you have to keep it as simple as you can. The first few times your child visits the centre, stay close to home and be readily available on the phone to answer any questions they might have

## **Everyone Involved with Your Child or Child's Care**

Discuss the ketogenic diet therapy with everyone involved with your child's health: visitors, social workers, babysitters, respite workers, etc. Make sure everyone knows, as this will reduce the chance of mistakes being made and 'extras' or 'treats' being given to your child. It will also help you to know that you have covered everything.

## **4. Ask Questions!**

Never stop asking questions. Even if you think they sound unimportant, ask it anyway. If it is worrying you, then the subject matter (whatever it is) needs to be addressed. There is no such thing as an unimportant question if it is worrying you.

## **5. Preparing Yourself / Your Child for the Diet**

Before you actually start the diet, the following suggestions may help to gradually ease into ketogenic diet initiation:

- ✓ Slowly reduce and eliminate all cakes, cookies, candy and chocolate
- ✓ Swap full sugar varieties of drinks with sugar free alternatives (look on the label for trace carbs or less than 0.4g per 100mls).
- ✓ Try sugar free jello made with whipping cream to make a creamy dessert.
- ✓ Use whipping cream in your coffee instead of milk.
- ✓ Try herbal teas, such as peppermint.
- ✓ Swap sugar for sweeteners.
- ✓ Try different vegetables and experiment (example celeriac ie celery root can be used like mashed potatoes and is extremely tasty).



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- ✓ Have bacon and egg for breakfast or an omelette instead of cereals.
- ✓ Put butter on your vegetables or meat.
- ✓ Make some creamy sauces to go over your dinner such as a simple one made with whipping cream, mushrooms and butter.
- ✓ Use whipped cream to dip fruit or add as topping on sugar free jello
- ✓ Make hot chocolate or 'milk' using cream with water &/or cocoa
- ✓ Eat meals and snacks regularly if not already

A testing period may make life easier for you, your child, and your dietitian so she can make sure to incorporate the foods that you have been successful in trying into meal plans for diet initiation. Most of all it will help you, your child and family realize that there will be a variety of options to incorporate into your everyday family meals.

When the time comes to initiate the ketogenic diet, you may have to weigh things out on an electronic weigh scale at every mealtime – this will get easier with practice. You will have to be organised and keep your basic stock cupboard up to date. Once food preferences and preparation techniques are established, preparing batch recipes and freezing can be useful and time saving. Keep it simple to start with and as your confidence grows so will the variety of recipes you have.

*“Matthew was on the diet for nearly 6 years and yes, there were certainly days when I could have cheerfully thrown the scales out of the window but looking back now I certainly wouldn't have changed it and yes, it was all worth it. For some reason Monday evenings turned into my 'batching night' and I would put my little TV on in the kitchen or listen to an audio book whilst making quiches, muffins and cookies and before I knew it I had a freezer full and it would be another two weeks before I would need to make another lot. Sometimes the thought of doing it was worse than actually doing it”*

*Emma Williams, Mum to Matthew*



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## **EQUIPMENT YOU WILL NEED**

- 1. Electronic Scales** - All food items for the ketogenic diet may require measuring or weighing. A scale would be required to weigh quantities to **0.1 gram**. Take note of the maximum weight the scale goes to prior to purchasing scales as you may need to weigh larger amounts if using batch recipes. For scales to weigh accurately they should be on a completely level surface.
- 2. Baking/Measuring spoons** –Some foods and liquids require measurement in mls. Tableware teaspoons or tablespoons can often vary in their measurements and are not recommended.
- 3. Spare Batteries for Scales** - **ALWAYS** make sure you have a spare set of batteries in the house or even 2 sets, and immediately go out and buy a replacement set when you have used one of them. Don't believe the 'battery low' signal – it really means 'battery gone'.
- 4. Small Plastic or Glass Sealed Containers** - Containers with covers can be used to freeze meals to use at a later date.
- 5. Freezer Bags** - Very useful for 'batching up' and meal preparation. When needing several portions of any food, weigh out the appropriate amounts and put them in the little bags (with appropriate amounts of other ingredients for a recipe as well if you wish) and then put them in the freezer. When you are next preparing a meal you can just pull out a bag and defrost it and know that the ingredients are already weighed.
- 6. Plastic Spatulas** - Purchasing several of these is a good idea. These ensure that you can scrape every last bit out of the bowl you are eating from or pan you are cooking from.
- 7. Small Frying Pan** - As some recipes require small volumes, a small frying pan is useful. Non-stick varieties are preferred or use PAM (or other fat as part of the planned recipe) to prevent surface sticking.
- 8. Small Plastic Bowls** - Use these to weigh food out on the scales.
- 9. Small Cool Bag and Ice Pack** - For any packed meals for school/work or days out.
- 10. Freezer Labels and Permanent Pen** - Good for writing down what ingredients or meals are contained in your plastic or glass containers and your freezer bags along with the date and if anything needs to be added.



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If you have any questions please connect with your ketogenic diet team or Matthew's Friends Canada. Other publications are available to support you. Feel free to contact us:

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