



Parenting Your Child on the Ketogenic Diet

The ketogenic diet is a change for the whole family. These are some things to consider as you think about whether to try the ketogenic diet, or prepare to begin the diet.

Your child on the ketogenic diet

Each child responds differently to being on the ketogenic diet. But there are some effects that many children have in common. Some of the effects happen when your child is starting the diet or when there is a calorie or ratio change. Some effects may go on for a longer time. It is always important to let your child's dietitian or doctor know if your child has:

Physical:

- Hunger (or loss of appetite)
- Thirst
- Low energy

Social and emotional:

- Anger and frustration
- Feelings of deprivation
- Feeling different than other kids

If your child has any discomfort or frustration on this diet, it can be very painful to stick to the rules. It is important to think about how you will talk to your child when they want more or different foods. Some parents have found it is helpful to tell their children that this is a “magic” or “special” diet that makes them have fewer seizures. Talking about how badly the seizures made you both feel can help with motivation.

It is likely that after being on the diet a short time, you and your child will become extra aware of food. You will notice how it is advertised in the media and how it is used for celebrations like birthdays and holidays. You may notice how it is part of activities like watching movies or TV. You may also become aware of your own habits and feelings about food and parenting. Is it your instinct to comfort your child with food when they are upset? It's helpful to reflect on your own beliefs and actions around food. This can help make you more aware of ways to support your child and family as you shift to life on the ketogenic diet.

Here are some suggestions from other parents of children on the ketogenic diet. Before you begin the diet you may want to think about your ideas for helping your child and family be successful on the ketogenic diet.

- **Talk with your child often about how hard it is to be on the diet.** Listen to your child's feelings and say often how proud you are that they are doing such a great job on the diet.

To Learn More

- Neurology
206-987-2078
- Your child's
healthcare provider
- www.seattlechildrens.org

Free Interpreter Services

- In the hospital, ask your child's nurse.
- From outside the hospital, call the toll-free Family Interpreting Line 1-866-583-1527. Tell the interpreter the name or extension you need.
- For Deaf and hard of hearing callers: 206-987-2280 (TTY).

- **Give up something yourself.** Try giving up some of your favorite foods like sweets. This will help you share in your child's experience.
- **Find ways to enjoy being together as a family that don't involve food.**
- **Plan ahead for events, parties and holidays.** Think of other ways to celebrate besides food and give other non-food gifts like small toys or books. Give these to your child's teachers or neighbors in advance.
- **Throw away, give away or move foods that will tempt your child.** Try not to eat these foods around your child.
- **Set realistic expectations for the diet and celebrate your success!** Create a chart that shows how many seizures your child had before the diet, and how many they have had after the diet. This will show you the improvement your child has made.
- **Reward your child for doing a great job.**
- **Look for patterns related to your child's seizures.** Keep a record of your child's meals, medicines and seizures and work with your child's dietitian to fine-tune the diet for maximum success.
- **Prepare brothers and sisters and other close family members.** Help others in the family know how important it is to strictly follow this special diet, and tell them that you need their help. This means they cannot share food or give food or drink to their sibling. You may also want to create some new family rules about eating if you think your child on the ketogenic diet will be upset watching a sibling or parent eating certain foods.
- **Teach other adults in your child's life about the ketogenic diet.** You can request a letter for teachers from your child's ketogenic dietitian or nurse coordinator. You can adapt this letter so that it meets your needs.
- **Find support for yourself, too.** Many parents find it helpful to connect with others who can share your experience. Below are some Web sites and places in the community to find support.

Resources

- **The Charlie Foundation:** Information, more resources and frequently asked questions about the Ketogenic Diet. www.charlifoundation.org
- **Ketogenic Diet Support Group-Yahoo:** An online support group for parents, family members, and caregivers who are using the ketogenic diet to control seizures. www.health.groups.yahoo.com
- **Parent Support Program at Children's Hospital:** A one-on-one peer support program for families who are beginning to learn about their child's special health care needs. The program connects trained volunteer parents who have been through a similar experience with their own child. Contact Lawrie Williams at 206-987-1119.

Seattle Children's offers interpreter services for Deaf, hard of hearing or non-English speaking patients, family members and legal representatives free of charge. Seattle Children's will make this information available in alternate formats upon request. Call the Family Resource Center at 206-987-2201.

This handout has been reviewed by clinical staff at Seattle Children's. However, your child's needs are unique. Before you act or rely upon this information, please talk with your child's healthcare provider.

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