



Your Child's Hospital Stay to Start the Ketogenic Diet

What you and your child can expect

How long will my child be in the hospital?

Your child will most likely have to stay in the hospital for 3 nights and 4 days. Most families check in on a Tuesday and go home on Friday.

If it is hard for your child to adjust to the diet, they might need to stay a few days longer.

What will happen to my child while we are in the hospital?

Starting the diet

Your child will begin the diet on their first day at the hospital. A staff member in charge of bringing meals (dietetic technician) will bring ketogenic meals to your child's room. It is important that your child eats all of the food that the diet technician brings.

Tests and labs

Your child's doctor, nurse, dietitian or other members of the healthcare team will check on how your child is doing each day. They will check:

- Your child's urine for ketones. They will use special strips that show how deeply your child is in ketosis. If your child is potty trained, they will pee into a small tub or basin and the strip will be dipped in the urine to check ketosis. If your child wears diapers, a cotton ball will be placed in the diaper, and it will be wrung out to check urine.
- Your child's blood sugar with a finger poke every 6 hours.
- Your child's blood ketones once a day by taking some blood from a vein (venous blood draw).
- Your child's vital signs like heart rate and blood pressure. This will happen many times a day.
- Your child's doctor might need to order some other tests. Your child's healthcare team might need to do other finger pokes or blood draws.

Your child's feelings and what to expect

Your child might feel tired during the first few days or weeks after starting the diet. This usually goes away.

At the beginning of the diet, your child will probably feel hungry. For the diet to work, it is important for your child to get into a deep state of ketosis. This means that calories will be restricted and portions will be limited. Your child's portions are smallest in the first days of the diet. Your child might feel angry or upset about this, or about eating different foods than they are used to. Most children stop feeling hungry after their bodies get used to the diet.

While you are at the hospital, you might want to eat your meals away from your child while they adjust to starting the diet. There are several options for where you can eat. You might want to eat in the hospital cafeteria or in the Family Resource Center. You can refrigerate or heat up your food in the family lounge near your child's hospital room.

Starting the diet can be stressful for your child. Try to spend a lot of time with your child. One parent should plan to spend the night with your child.

Other things that might happen

Your child might feel like throwing up (feel nauseated), and might vomit when they start the diet. Your child's healthcare team will change the diet or treat your child to fix this problem.

Your child might have more seizures than usual when they start the diet. This is because of the extra stress on your child when there are big changes in their body. It can also be stressful for your child to be in the hospital. These things all often get better as your child gets used to being on the diet.

Learning more about the diet when your child is at the hospital

A dietitian who knows a lot about ketogenic diets (ketogenic dietitian) will teach you what you need to know about the diet. You will also get a notebook with information about the diet, and also a special scale (a gram scale) for measuring food.

The ketogenic dietitian will hold one-on-one or group classes. Some of the things you will learn about are:

- How to weigh foods using a gram scale
- How to make meals and recipes that fit into the diet
- How to tell when your child has problems related to the diet (hyper-ketosis low blood sugar, also called hypoglycemia)
- How to treat these problems
- When to call for help
- How to keep track of seizures that your child has while on the diet. This helps the healthcare team make changes to help control seizures better
- How to deal with common problems
- How to manage the ketogenic diet when your child is sick

It is important to arrange for a friend or family member to care for your child during these classes. It is best when you can focus all your attention on learning about the diet. Hospital volunteers may be able to stay with your child. Ask your child's nurse about getting a volunteer to stay with your child.

Please let your child's dietitian know if you cannot be at the hospital at any time. This will help them schedule the classes.

Who is on my child's care team?

In addition to the doctors and nurses on your child's health care team, these are some of the people who will be involved in your child's care:

Dietitian

In the hospital, your child will have two dietitians who know a lot about the ketogenic diet. When your child goes home, one of these dietitians will become your child's main ketogenic dietitian. This dietitian will follow up with you and see your child for appointments. They will also be your main contact person as you learn how to manage the diet.

Dietetic Technician

The ketogenic dietitian supervises a dietetic technician. This person will prepare and bring your child ketogenic meals while they are in the hospital.

Doctors

Children's is a teaching hospital, so when your child is in the hospital you will see many doctors. They will include attending doctors, fellows, residents, and sometimes medical students. The doctors who may see your child are:

- **Attending doctors** have had extra training and experience taking care of children with neurological problems. They teach other doctors to care for children with seizure disorders.
- **Fellows** are pediatricians (doctors for children) who are doing extra training to learn how to care for children with neurological problems (including seizure disorders).
- **Residents** are doctors training to be pediatricians.
- **Medical students** are learning to be doctors. They work under the close supervision of the rest of the doctors on the team.

Nurses and other healthcare professionals

Neurology Nurse Practitioners

Nurses with advanced training (ARNPs) will help you to handle many of the issues that come up while caring for your child at home and while in the hospital. A nurse practitioner will see your child in the clinic. Your nurse practitioner can answer your questions about:

- Seizure protocols, medication schedules and treatment plans
- Taking care of your child at home
- When to get labs drawn (and which labs are necessary)
- Prescription refills and medicine changes, including ketogenic diet adjustments
- Letters and forms regarding medical care
- Any other concerns or worries you may have

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).

Staff nurses (RNs)

Staff nurses will care for your child in the inpatient unit during this hospitalization. They will give much of the direct care your child needs, including medicine if your child has a seizure. Staff nurses are able to be in touch with your child's doctors and other practitioners.

Neurology Nurses (RNs)

Neurology Nurses (RNs) will work with you in Neurology clinic visits and on the phone with you when you return home to help your child adjust to the diet.

Social workers

Social workers help families adjust to the challenges they face because of their child's illness. They are able to provide individual family support and counseling, and can give information about community and hospital resources (including financial aid). Social workers serve as an advocate to get items and services your family needs. If you would like to work with a social worker, ask your child's staff nurse.

Pharmacists

Pharmacists help make sure that your child's medicines are appropriate for the diet. If your child takes chewable medicines or liquid medicines many of these may change to crushable pill form when you start the diet. Be sure to always tell any pharmacist you work with that your child is on the ketogenic diet!