

Ketogenic Diet Education Plan

Getting Ready to Learn About Ketogenic Diet

Learning something new can be hard. It is even harder if you are not feeling well. The purpose of this education plan is for you and the staff to review this information together. Here are some good things to tell the staff:

- Who you want to learn with you. We would like to have someone who will be helping you at home learn with you.
- The best way for you to learn. Do you learn best by reading a book or pamphlet, or by doing things yourself?
- If you are not feeling well, if you are in pain or you cannot focus on learning right now.

This information is important to your health. We may explain something more than once. We will be giving you information in small bits over several days. If there is something you don't understand, "It's OK to Ask" us to explain.

What I Need to Learn About Ketogenic Diet

By the time I leave the hospital I will be able to show or tell the staff:

1. What a Ketogenic Diet is.
2. How the Ketogenic Diet works.
3. How long I will be on the Ketogenic Diet.
4. What supplies I will need and how to get them.
5. How to start my Ketogenic Diet.
6. How to take care of myself while I am on the Ketogenic Diet.
7. How to monitor myself while I am on the Ketogenic Diet.
8. How I will manage the Ketogenic Diet when I am sick.
9. What the side effects of a Ketogenic Diet are.
10. When I will follow up with the neurologist and dietitian.

The staff will use three questions to teach me about Ketogenic Diet:

1. What is my main problem?
2. What do I need to do?
3. Why is this important to me?

The staff will ask me to repeat back important points in my own words, or ask me to show what I have learned. They want to make sure that I know about my medication and how to take it safely and correctly.

What is my main problem?

I have seizures that are not controlled with medicine. My doctor recommends that I start a Ketogenic Diet. The Ketogenic Diet can help control seizures when medicines alone do not help. It may take at least 3 months before I see my seizures improve.

What do I need to do?

I will be able to tell the staff what a Ketogenic Diet is.

- Most of the diet consists of a tube feeding called KetoCal.
- This diet is:
 - Very low in carbohydrates, high in fat, and low in protein.
 - Used by both children and adults to help treat seizures.
 - Used when medicines and other treatments do not work.
 - Carefully calculated for each person.
 - Used only under a doctor's care.

I will be able to tell the staff how the Ketogenic Diet works.

- When my body does not have sugar to use for energy, it uses fat instead.
- When fat is used for energy my body makes ketones.
- A high amount of ketones in my body is called ketosis.
- Ketosis may decrease my seizures.

I will be able to tell the staff how long I will be on the Ketogenic Diet.

- I will be on the Ketogenic Diet:
 - For at least 3 months before my doctor will know if it is working to control my seizures.
 - For years if the diet helps control my seizures.

I will be able to tell the staff what supplies I need and how to get them.

- KetoCal - I will ask the neurology staff how to get this formula. I cannot buy it in a store.
- Ketostix - I will get a prescription and pick them up at my pharmacy. The pharmacy may need to order them.

- Gram Scale - I will need a scale to measure KetoCal powder. I will buy a scale that measures to the nearest 0.1 gram at a store or online.

I will be able to tell the staff how to start my Ketogenic Diet.

- I will start my Ketogenic Diet by:
 - Fasting for 24 hours. This helps use up all of my body's sugar.
 - Checking my urine for ketones.
 - Starting tube feedings of KetoCal. The dietitian and doctor will work together to figure out how much formula I need. The amount will slowly increase over three days.
 - The dietitian will help make a feeding plan that works well for my family and me.

I will be able to tell staff how to take care of myself while I am on the Ketogenic Diet.

- I will stay in ketosis by using KetoCal formula as prescribed.
- I will make my KetoCal formula correctly by:
 - Using my gram scale (for powdered KetoCal).
 - Exactly following the dietitian's instructions for preparing my KetoCal formula.
- I will check my medicines and other products for carbohydrates.
 - I will ask my pharmacists to review all of my medicines to find ones with the lowest carbohydrate content.
 - Most medicines can be changed or made carbohydrate free.
 - If a medicine cannot be changed, I will find out exactly how many carbohydrates are in it and tell my doctor.
 - I will use carbohydrate free toothpaste.
 - I will tell my caregivers that I am on a strict diet.
- I will not eat anything that is not on my Ketogenic Diet.

I will be able to tell the staff how I will monitor myself while I am on the Ketogenic Diet.

- I will check my urine for ketones:
 - Twice daily until my doctor tells me to stop.
 - By placing a small amount of urine on the Ketostix.
 - My urine should have moderate to high ketones.
 - I will record my results on my Urine Ketone and Seizure Log sheet.

- I will write down whenever I have a seizure on my Urine Ketone and Seizure log sheet. The doctor needs to know how many seizures I have so that my feedings can be changed if needed.

I will be able to tell the staff how I will manage my Ketogenic Diet when I am sick.

- I need to take in enough fluid and avoid carbohydrates even when I am sick.
- During the first 24 hours, I will take clear liquids such as :
 - Pedialyte (unflavored) full or ½ strength.
 - Water.
 - Bouillon cube dissolved in water.
- During the second 24 hours, if I tolerate clear liquids, start half strength KetoCal:
 - Mix _____ KetoCal powder with _____ water.
 - Give _____ times/day.
- On the third day, if I tolerate half strength KetoCal for 24 hours, take my usual full strength KetoCal diet.
- I do not have to routinely monitor my blood sugar.
- My blood sugar should be low, but I should not have symptoms of low blood sugar. My caregiver or I will call the doctor's office if I have symptoms of low blood sugar:
 - Clammy
 - Shaky
 - Dizzy
 - Anxious
 - Blurred vision
 - Weak or fatigued
 - Unresponsive
- If I am hospitalized for illness or have dehydration, and my blood glucose is
 - 40 mg/dL or below, the hospital staff may start an IV with fluids that contain dextrose (sugar).
 - Above 40 mg/dL, the hospital staff may start an IV with fluids that **do not** contain dextrose. This fluid is called normal saline.

I will be able to tell the staff the side effects of a Ketogenic Diet.

- I may or may not have side effects from the Ketogenic Diet. Side effects may include:
 - Nausea, gas, constipation or diarrhea
 - Kidney stones
 - Acidosis (build-up of acid in the body). This usually clears after the first few weeks.
 - Pancreatitis—inflammation of the pancreas.
 - Decreased bone density.
 - Irregular menses in teen and adult females.

I will be able to tell the staff when I will follow up with my neurologist and dietitian.

- I should take my seizure log, urine ketone log and medicines to all of my follow-up appointments.
- I should make appointments with my neurologist/neurology pediatric nurse practitioner who will ask about side effects and seizures. I will:
 - Make my first appointment 4 weeks after starting the diet.
 - Have my lab work done 1 week before the appointment.
 - Schedule an appointment:
 - Every month for the first 3 months after starting the diet.
 - Six months after starting the diet, and 9 months after if needed.
 - After the first year on the diet, every 6 – 12 months as long as I am on the diet.
- I will see or talk to the dietitian (RD) who will watch my growth and change my diet as needed:
 - Phone follow-up 2 weeks after starting the diet.
 - In-office follow-up at each appointment with neurologist.

Why is this important to me?

If I stop the ketogenic diet for even one meal, it may lose its good effect. It is very important to follow the diet exactly as prescribed. If I follow this diet carefully, my seizures may be better controlled.

As part of my care and to help me understand my Ketogenic Diet I have received the Ketogenic Diet Education Plan. I may also receive:

- Physician Specific Ketogenic Diet Overview
- Physician Specific Ketogenic Diet Discharge Instructions
- Dietician Specific Ketogenic Diet Instructions
- Sick Day Guidelines

Other resources for families include:

- The Charlie Foundation: www.charlifoundation.org
- The Ketogenic Diet: A Treatment for Epilepsy by John M. Freeman, MD, Jennifer B. Freeman, and Millicent T. Kelly, RD, LD.

Ketogenic Diet Education Plan

Resources

- [Epilepsy Foundation-Ketogenic Diet](#)
- [The Charlie Foundation-Ketogenic Diet](#)
- [Lexi Comp Online-Ketogenic Diet](#)

Teaching Tools

- Ketogenic Diet Education Plan
- Physician Specific Ketogenic Diet Overview
- Physician Specific Ketogenic Diet Discharge Instructions
- Dietitian Specific Ketogenic Diet Instructions
- Handout: Ketogenic Diet Supply List
- Handout: Going Home on the Ketogenic Diet
- Handout: Testing Urine Ketones
- Handout: Urine Ketone and Seizure Log
- Handout: Sick Day Guidelines
- Handout: Medicines While on the Ketogenic Diet
- Handout: Carbohydrate

References

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- Epilepsy Foundation. (nd). Ketogenic Diet. Retrieved from <http://www.epilepsy.com/learn/treating-seizures-and-epilepsy/dietary-therapies/ketogenic-diet>. April, 2014.
- The Charlie Foundation for Ketogenic Therapies. (2014). Classic ketogenic and modified ketogenic. Retrieved from <http://www.charliefoundation.org/explore-ketogenic-diet/explore-2/classic-ketogenic>. April, 2014.
- Ketogenic Diets: Treatments for Epilepsy and Other Disorders, 5th Edition by Eric H. Kossoff, MD, John M. Freeman, MD, Zahava Turner, RD and James E. Rubenstein, MD. New York: Demos Medical Publishing, 2011.

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Always close each teaching session with the question, “What questions do you have for me?”

*This page is intended for staff use only. Do not give to the patient. This document is not a part of the permanent medical record.