

# Sticking to a Special Diet Without Getting Stuck

Enhance Your Child's Adherence to Special Diets  
*A Guide For Parents of Children With Metabolic Disorders*



**Boston Children's Hospital**  
Until every child is well™

## Dear Parents and Caregivers,

By now, you know the importance of helping your child follow medical recommendations, like eating a low-protein, low-fat, low-carbohydrate, or dairy-free diet and taking enough supplements or formula. This guide is here to remind you of ways to help your child stay on track now and in the future. Since sticking to the diet presents different challenges at every stage of life, we hope this guide is helpful for parents of children of all ages.

This guide is for parents of children with any metabolic disorder that requires a restricted diet. Families with the following conditions helped shape it:

- Phenylketonuria (PKU)
- Urea Cycle Disorders
- Galactosemia

We hope the information we offer will support you in your efforts to raise a healthy child who sticks to his or her medical recommendations. Our ultimate goals are to help your child:

- Establish an identity separate from the condition
- Reach full potential and optimal health through proper nutrition
- Be happy and socially engaged
- Become independent

Sticking to a Special Diet Without Getting Stuck was developed in collaboration with Emerson College's Health Communication program. Many thanks to the patients, providers, and parents who contributed their insights.

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# What Are Metabolic Disorders?

Metabolic disorders, or inborn errors of metabolism, are rare genetic conditions that prevent the body from breaking down certain elements of food, such as protein, fat, or carbohydrates, or certain types of food, like dairy. These conditions are inherited and are present from birth.

Babies are tested for metabolic disorders through routine newborn screening, so doctors and families usually know about the condition early on. Although new management options are on the horizon, current treatment for these conditions typically involves following a special diet (of low-protein, low-fat, or dairy-free foods) and making up for the missing nutrients by taking formula or supplements.

Helping children follow their diet and other medical guidelines is key in making sure they grow into their best physical, social, and emotional selves.

Although each inborn error of metabolism is unique, people with any of these conditions are better off when they stick to the diet and take enough supplements or formula. Following these guidelines helps improve growth, brain development, and mood. Following the diet for the first six years of life is most important for preventing severe brain damage, but staying “on-diet” for life is best for reaching full physical and mental potential.

## The Challenges...

Sticking to a diet—whether by choice or doctor’s orders—can be hard, especially when going “off diet” may not lead to pain or immediate physical consequences.

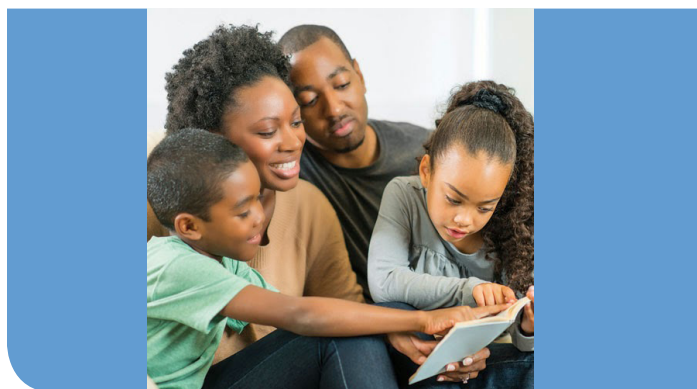
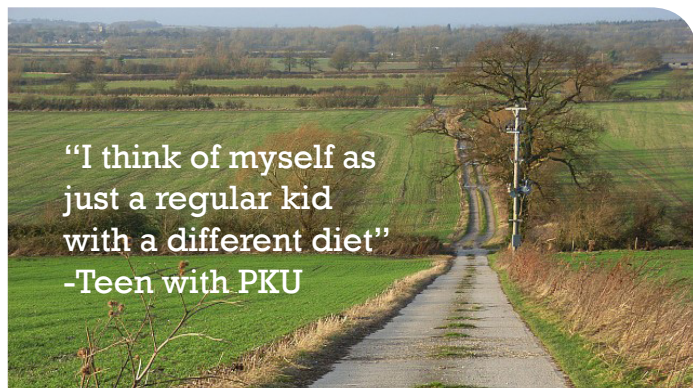
Plus, having to keep track of a “special diet” or take “special supplements” can be tough. Children don’t want to be different. From not being able to eat cupcakes at birthday parties or pizza at school, to following a formula schedule, to having to order French fries and a salad instead of a burger while out to eat with friends, kids with metabolic disorders face many challenges that can get in the way of following the diet.

This guide aims to support parents in their mission to raise happy, healthy, independent children who are able to make good choices now and in the future.

# Different Diet, Same Needs

Whether your child has to eat low-protein, low-fat, low-carb, or dairy-free food, his or her need for a healthy diet is the same.

Think of the special diet as a different vehicle for helping your child reach the same destination: a healthy mind and body.



Keep in mind that diet guidelines may change over time.

Formula, supplements, and other special products help your child make up for the nutrients he or she may be missing out on. This helps them feel better overall.

For example, when "on-diet," patients report these improvements:

- ❖ PKU
  - More energy
  - Less anxiety
  - Better focus and mood
- ❖ Galactosemia
  - Less stomach pain
- ❖ Urea Cycle Disorders
  - Better focus and sleep

Have you noticed any differences in behavior or mood when your child is on or off-diet?

Your role as a parent of a child with a special diet may change, too. For example:

- ❖ In general, older children have more difficulty maintaining metabolic control. This means that paying attention to the diet and special formula is a lifelong task.
- ❖ People with galactosemia may be instructed to introduce some dairy products, like hard cheeses, as they age.
- ❖ Diet guidelines may change as new treatments become available.



## Focus on Your Child *Not The Condition*

Most people with metabolic disorders will stray from their diet at some point. Research shows that as children age and gain independence, they are more likely to try restricted foods and skip their formula. Knowing that this may happen can help you prepare to work on it with your child. You can let your child know that you are always there to support him or her. Here are some other steps you can take:

### ❖ **Help your child build an identity beyond the condition.**

- o Although your child may have fewer food choices than his or her siblings, friends, or classmates, he or she can have just as many hobbies, responsibilities, and choices in other areas of life. Your child's condition should determine what they eat, not who they are.

### ❖ **Talk to your child about something other than food.**

- o What makes your child unique? What are his or her strengths? Point out what he or she is good at while keeping diet out of the conversation.

### ❖ **Remember that going off diet is part of the cycle.**

- o While it's important for children to follow the diet and formula requirements, research shows that being too strict with the diet does not help children stick to it in the long run.
- o It is natural for children to want to try restricted foods, especially when they are old enough to go out to eat with friends. Throughout these ups and downs, keep your message the same: "I'm here for you."

"When I grew up, my parents always thought that everything was related to my PKU... like my mood or my grades, or if I had bags under my eyes. I hated that."

– Adult with PKU





# Drama-Free Diet

Whether your child's diet is low-protein, low-fat, low-carb, or dairy-free, **it shouldn't take center stage.**

## ❖ Keep emotion out of food.

- o What your child eats is certainly important, but try to think of each meal as just another meal. If you fixate too much on the food your child eats, he or she may learn to leverage the power!

## ❖ Educate your child.

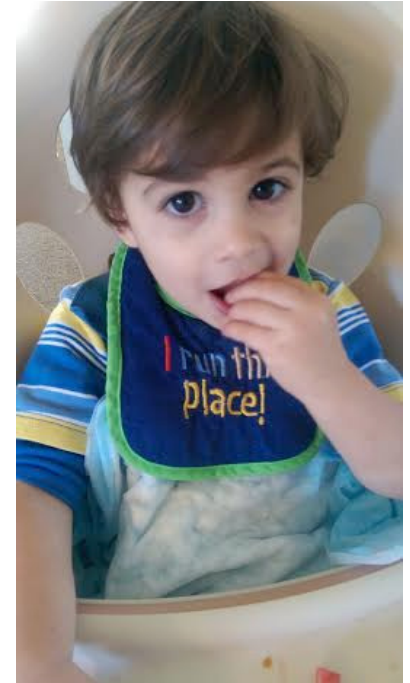
- o The better your child understands why he or she has to eat special food, the more likely he or she is to follow the diet.

## ❖ Help your child get social support.

- o Look into summer camps, social groups, and other activities where your child can meet other children with similar conditions.

## ❖ Present food and formula in normal ways.

- o Try to make food look and taste as normal as possible. For example, serve your child low-protein pasta and meat-free sauce when you're having pasta night for the whole family.
- o Dress up food with fun flavors, like different sauces, fresh fruits, or colorful veggies.



*Child with PKU*

## ❖ Look into low-protein, dairy-free, or other alternative food options.

- o There are hundreds of low-protein and dairy-free products on the market today. Incorporate these products in your child's diet to provide more variety and "normal" options.

See page 9 for a full list of resources for special diets.



Get creative in the kitchen!

One parent makes "Super Sonic Sandwiches," packed with different veggies and dressings, for all of his kids. The PKU version? No deli meat.



“Make sure children are also aware and informed... Make sure they can inform friends on their own.”

-Young adult with PKU

## Throw Out The First Pitch

Provide your child with a cafeteria or birthday party “pitch” – just one or two short sentences – so that he or she can explain the diet to classmates and friends.

### Here are some general guidelines:

- ❖ Frame the condition in a positive way.
- ❖ Keep your explanation simple. Build on it as your child grows and can understand more.
- ❖ Help your child practice explaining the condition to friends and classmates.

### Sample Pitches

PKU or Urea Cycle Disorder (low-protein)

- ❖ “My body can’t break down the protein in foods like meat, fish, and beans, so I eat foods that don’t have too much protein, like fruits, vegetables, and a special drink for energy.”

Galactosemia (dairy-free)

- ❖ “My body can’t process dairy, like milk, cheese, or ice cream, so I drink soy milk and eat dairy-free foods instead.”

“The attitude parents have will be the one that their children will continue to have as they independently live their teen and adult lives dealing with PKU.”

– Adult with PKU





# Resources

## Information and Social Support

### New England Consortium of Metabolic Programs

- ❖ This website features information and resources from a variety of health professionals aimed at providing care for people with metabolic disorders.  
<http://newenglandconsortium.org/>

### Next Step

- ❖ This organization provides year-round support and resources for young people with chronic conditions during their transition to adulthood.  
<http://nextstepnet.org/>

### The Hole In The Wall Gang Summer Camp

- ❖ This week-long camp in Ashford, CT offers children with chronic conditions the opportunity to bond with other children with similar conditions and improve their self-management skills.  
<http://holeinthewallgang.org/programs/summer-camp/>

## Alternative Food Companies and Recipes

- ❖ Cambrooke Foods - <http://cambrookefoods.com>
- ❖ Cook For Love - <http://cookforlove.org>
- ❖ Dietary Specialties - <http://dietspec.com/>
- ❖ Ener-g Foods - <http://ener-g.com/>
- ❖ Med-Diet - <http://med-diet.com/>
- ❖ Nutricia Metabolics - <http://medicalfood.com/>
- ❖ PKU Perspectives - <http://pkuperspectives.com/>
- ❖ Taste Connections - <http://tasteconnections.com/>

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This guide was created in collaboration with the Metabolism Program at Boston Children's Hospital, and with support from New England Genetics Collaborative

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*Child with Galactosemia*