

Feeding a Phe-Restricted Diet

Feeding your baby a Phe-restricted diet is easy. You feed the formula in a bottle, just like any other baby. It may be possible to alternate breast feeding with medical food feeding depending on your baby's Phe allowances. Ask your baby's dietician if this is a possibility in your child's case, and together, you can work out the feeding schedule that will be most beneficial for your baby.



As your baby grows you will begin introducing solid foods to your baby. Once again, the only difference is *what* is fed. Allow your baby to experiment with feeding herself finger foods such as low protein crackers, and with learning to use a spoon to eat appropriate cereals and baby foods. Don't worry if she doesn't eat all the foods you measure out, just estimate what was not eaten and write it down. It may take her a few tries to get used to a new food. If she is still hungry, measure out another kind of food for her to eat. Your nutritionist realizes that your baby may get more food *on* her than *in* her and will help you measure accordingly.

For an older child, the differences between the Phe-restricted diet and the diets of other children will be greater. Your child with PKU will require the medical food throughout her life to provide most of the needed protein, vitamins, and minerals. The formula can be sent to school as a "special milkshake" for lunch, and supplemented with other measured foods. Make sure your child knows to bring any leftovers home for you to measure, until she is old enough to do it herself. At your child's clinic visits, you will work with the nutritionist to plan out your child's diet and fit it in with the needs of the rest of the family. You will learn what foods your child can eat, and in what amounts, and how much of the medical food to give to supplement her diet. Serving lists (or food lists) are lists that show the amounts of Phe and protein in specific foods, and will be provided to you. These make meal planning for your family easier and help you be sure your child's nutrient needs are met.

Your Child's Diet During Illness

When your child is sick, especially with a fever, the body's rate of using energy speeds up. If extra energy isn't supplied during illness, the body will break down its own muscle protein and fats stores and to use for energy. If this happens, Phe in the muscle protein is released into the body in amounts that are too high for a child with PKU to use. Your child will need extra food during illness so the body can use it for energy instead of muscle protein.

Feeding an ill child can be very difficult due to restlessness, loss of appetite, nausea and vomiting. An ill child may also become dehydrated because of fever and inadequate fluid intake. You should call your child's pediatrician as soon as possible if he or she has a fever. Ask about giving your child medication to reduce fever, and fluids to prevent dehydration. If your child is unable to maintain proper nutrition, he or she may need to be admitted to the hospital for intravenous nutrition.



Here are some nutrition tips for when your child is sick with a fever:

- ◆ Don't force feed food or formula, especially if your child is nauseated or vomiting. Formula may be diluted or flavored if this will help your child drink it.
- ◆ Offer Pedialyte® or other electrolyte solutions, non-cola carbonated beverages, tea with sugar, fruit juices, liquid gelatin mix or any other approved liquid your child will drink.
- ◆ Freeze any of the beverages above and offer as ice chips or popsicles.