



Chapter 6: Ages 7 to 12 Years

A Parent's Perspective

"I have to go to the hospital every 6 months. I get really excited because I get to miss one whole day of school! I go all the way to Toronto to visit my dietitian... She suggests new foods and makes adjustments to my formula. She also tells me how my protein levels have been. After I visit her, I usually go to Doctor Feigenbaum [sic]. She tests my abilities and sees how much [PHE] concentration I have. And then comes the worst part of going to Children's Hospital. I have to get a needle...to see how much protein I've had. I also have a pen at my house that I use to prick my thumb every month and then I send a sample of my blood to the hospital, and they send me my protein levels. I think going to Toronto is one of the best parts of having PKU."

What to Expect

At this age, the focus of a child's life expands beyond family life to include relationships with peers, teachers, coaches and others. This is an exciting time for you and your child as their "world" begins to expand. Having provided them (and those around them) with all the information you have about PKU and their special low protein diet, you are likely feeling quite confident about your child with PKU and his or her ability to go out in the world as independently as they can at this age!

As your child begins to experience his or her expanding world, he or she will encounter new and enticing foods. Some parents may begin to feel a sense of guilt around their child's low Phe diet and not being able to allow your child to have these exciting foods. Like any parent, you want to be able to give your child a small treat. It's important you don't give in to this sense of guilt by giving treats that aren't low in Phe. Don't forget, there are treats that your child can enjoy without compromising their diet. By ensuring your child doesn't over-indulge in these treats, they will remain just that – fun treats you can give your child when he or she needs a little celebration, pick-me-up or change in their regular diet! Enjoy it with him or her and the entire family!

Development

Children of this age spend more time with their friends and often rely on peers and others outside their family for information. During this time, social connections for children with PKU are critical²⁷ as children with PKU often report feeling socially isolated²⁸. Encouraging social connections now will help your child develop a strong social network for the teen years, when social support becomes even more important for their well being and development.

During this time period, the academic demands on children increase. Schoolwork shifts from a focus on memorization to using knowledge for problem solving. Children of this age develop the ability to apply logic to solving concrete problems; parents can help encourage

²⁷ Advocates for Youth. "Growth and Development, Ages Six to Eight—What Parents Need to Know" Available at: http://www.advocatesforyouth.org/index.php?option=com_content&task=view&id=154&Itemid=206 Accessed May 17, 2011

²⁸ Jusiene R, Cimbalistiene L, Bieliauskaite R. *Psychological adjustment of children with phenylketonuria Medicina* (Kaunas) 38 (2002) 424-430

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this skill by asking questions to prompt problem solving, such as²⁹:

- “What are you being asked to do?”
- “What do you know?”
- “What information will help you?”
- “Is your approach working? Should you try something else?”

It is not uncommon for children of this age to resist some aspects of their treatment³⁰. For this reason, it is especially important for parents to continue encouraging your child’s involvement with treatment, such as making formula and preparing their filter cards. Talking to your child about how he or she will handle the PKU diet and treatment at school is also very important at this age. While the school staff will do their best to supervise, you will feel more secure if your child understands and is able to help manage her own diet appropriately.

Things to talk to your child about include:

- Foods that are OK and foods to avoid.
- Bringing home uneaten food in his or her lunch box so that you can calculate milligrams/exchanges for the day.
- Not swapping lunch food or drinks with friends.
- Deciding when to drink medical formula during the school day and how to do it.
- How to explain PKU and their diet and formula to other kids.
- What to do about teasing or embarrassment about the diet.

In addition, you should continue the process of helping your child learn how to manage PKU. Between seven and twelve years of age, your child will begin to manage – with your help – some aspects of her PKU. Helping your child begin to take responsibility for PKU now will help your child develop the competence and confidence to manage PKU throughout his or her life.

Treatment and Diet

Adherence to Diet

As children grow, they become more aware of those around them and notice people’s differences. It is normal for children of this age to place increasing value on peer acceptance and to want to be like their peers. Children with PKU may feel tempted to eat foods that are not on the PKU diet because they want to be like their friends or not call attention to

Children seven to ten years of age should work with parents on:

- *Preparing formula with decreasing supervision.*
- *Choosing an after school snack.*
- *Learning to pack school lunch.*
- *Beginning to list foods on a diet record.*
- *Beginning to weigh and or measure foods regularly.*

Children ten to twelve years of age should work with parents on:

- *Beginning to prepare and consume formula independently each day (with parental monitoring).*
- *Preparing simple entrees independently.*
- *Knowing what blood levels are ideal.*

-University of Washington. PKU and Self Management Timeline Available at: <http://depts.washington.edu/transmet/process/timeline.pdf> Accessed May 18, 2011

²⁹ Waisbren, S. Neurocognitive Functioning in PKU Illinois 2010 Presentation

³⁰ Waisbren, S. THE PSYCHOLOGY OF PKU and ALLIED DISORDERS (AND THE BOSTON MARATHON) National PKU Alliance Annual Parent Meeting, November 2009 Presentation

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themselves. In addition, children with PKU don't feel different or unhealthy, so they may question the need to stick to their diet or treatment as they don't "see" the effects of their PKU.



It is important for parents to reinforce to their child that he or she is healthy because of following the treatment plan. By sticking to the diet, formula and treatment, he or she will grow and be

able to do the things he or she wants to do. Talking about your child's goals – whether it is playing soccer in the spring or finishing a project for a class – may help your child see how diet and treatment is essential to achieving those goals.

A Parent's Perspective

"I used to tell my daughter, some people need glasses, some people are short, others are tall and you have PKU. You have to accept it and make it part of your life but having PKU is not your whole life."

A Parent's Perspective

"I pre-measure cereal, crackers, cookies, grapes, whatever, so that my child can make independent decisions about snacks."

Some suggestions for ways to help your child adhere to diet include:

- Exploring new formula options if formula in take becomes an issue.
- Having them more involved in the process of formula preparation. i.e. becoming more comfortable with using a gram scale and/or measuring utensils with parental supervision.
- Having your child bring formula to school in colored sports bottles or pre-made drink packs if available. This may help minimize interest or questions from other kids.
- Involving your child in meal planning and preparation. If she has some control over difficult aspects of her treatment, it becomes a shared responsibility and she will be more likely to stick to it.
- Letting your child choose her snacks or help you pack her lunch so that she has some control over what she is eating during the day.
- Keeping PKU meals similar to family meals so that your child feels a part of and included in the foods her family eats.
- Keeping low protein treats at school with your child's teachers so that your child has something to eat while others are celebrating a birthday or other event.
- Making sure that the child is comfortable asking for their low protein foods so that they do not get into the habit of sneaking foods.
- Including the child in Phe tracking/counting throughout the day and having them write foods in their diet records.
- Making sure that the child is aware of the importance of keeping their Phe intake within goal.
- Role playing with your child, asking her questions that other students might ask, such as "Why do you drink that milk?" and helping her work out responses she can use in different situations.
- At this age, children tend to be very active especially when involved with after school sports. That is why it is important to have a variety of low protein snacks available.

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"We started this process very young. My favorite idea was from our 3-year-old preschool teacher. She actually helped us make it. We made a tree out of brown construction paper and mounted it on a poster board. We then laminated the poster board. From there, we cut different colored leaves out of foam sheets (found in the craft store). On the back of each leaf, I put a circle velcro and the matching velcro was attached to the posterboard. Each colored leaf was worth a different number (e.g., 1, 5, or 10). Every night I would put the correct amount of PHE in leaves on the tree. Whenever she would eat something, we would take off the amount of PHE in leaves ('falling leaves'). It didn't take long for her to catch onto the concept."

Learning to Calculate Phe

A great way to teach your child how to calculate Phe is to count the milligrams/exchanges together. You may already be using a whiteboard or laminated paper with a chart to count the Phe eaten at each meal. You may start by writing the total amount of milligrams/exchanges their child can have each day at the top of the chart, and list meals under this amount. To encourage your child's independence, you can begin to get your child to list meals and the amount of Phe he or she can have each day.

Discuss with your child the milligrams/exchanges planned for that meal. Next to each meal, parents or children can write the milligrams/exchanges planned for that meal. As the milligrams/exchanges are eaten during the day, have your child cross them off. iPhone applications are also available for keeping track of Phe intake, including the DietWell application.

There are many other ways to create games or charts that help children count Phe – you can use your creativity or a solution that works for your family. The most important thing is that you work on counting Phe together so that your child begins to gain the skills he or she will need to manage PKU independently.

A Parent's Perspective

"Teach your child to measure/weigh her own 'milk' and be totally responsible for it by the time she leaves elementary school. Start this around age eight to nine by doing it in stages, maybe having her make her milk one to two times a week with supervision on the weighing. Once you are confident she can tackle the weighing, add quantity, then responsibility. Hopefully, by the time the child is 10 to 11 she will be making her milk on a daily basis with gentle reminders. Remember, they might not do it the way you do. For instance, I would measure out a week's worth in my son's containers, put the lids on and then the night before add the appropriate amount of water and put in fridge for the next morning. I made one mess with the weighing, cans, and scooper and then was basically done for the week. My son does it differently. About half the time he waits until the morning of to make it and the other half the time we get one measured the day before. I am learning very slowly to close my mouth and that other people do it differently."

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Bringing Formula to Class and Preparing Formula

Your child will most likely need to take her medical formula to school in order to spread intake throughout the day. Approximately, 1/3 of the formula for the day is an appropriate goal for formula consumption while at school.

- They can take pre-made formula in a fun sports bottle.
- Ready-made formulas such as Vitaflo Coolers are another option.
- Parents can talk with the teacher as to whether they would be allowed to drink some medical formula in class.
- They can go to the school nurse's office to drink formula.
- Pack the formula with the lunch and they can drink formula with their lunch.
- If they have after school activities, such as sports, they can have some formula then.

Blood Phe Monitoring

Goal Phe Range: 2-6 mg/dL (120-360 µmol/L)

Frequency

At this age you should check your child's Phe level every 2 weeks, unless directed otherwise by your clinic.

Tips for Taking a Blood Sample at this Age

From seven to twelve years, children can begin to take ownership over taking samples. Preparing them for this will help them to feel independent and confident. Tips for taking blood samples at this age:

- Have a calendar with the date marked when blood samples are taken to your child
- Continue to let your child choose which finger to use for the blood sample.
- Have your child fill out their name and date on the filter card.
- Encourage your child to press the button on the lancet pen.
- Ask what a correct sample looks like, and encourage your child to see how well he or she has done in producing a correct sample.
- Give lots of positive feedback on how well your child has done.
- By twelve, some children will be able to do this independently.

Quick Tip

Use topical 'numbing agents' such as Pain Ease[®] that help reduce the pain of the finger stick. Ask your PKU team if this is an option to use.

A Parent's Perspective

"I took my son to CVS and let him pick out a lancet device. Now he loads it and pricks himself. That has helped the process a ton."

Special Considerations

Preparation for Childhood Education

With pre-planning and communication between the family, school and PKU team, children with PKU can transition easily to a school setting. (See Chapter 4 for information on preparing for daycare).

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Each preschool or elementary school is managed differently. The following suggestions are a guide for planning and discussing your child's PKU management with school staff. Most clinics will also have a dietitian or nurse who can talk to the school to help with planning and to provide information on PKU.

Talking with School Staff

Letting your child's school and teacher know about his or her PKU is the first step. It is important for teachers and other staff to understand why your child needs a special diet, and why careful supervision is needed. Anyone who comes in contact with your child will need a basic understanding of your child's dietary restrictions. Some key points that you may want to include:

- PKU is a genetic condition that is not contagious.
- Apart from needing a special diet, a person with PKU is healthy.
- People with PKU cannot break down an amino acid called phenylalanine or Phe, which is found in all foods containing protein.
- Phe can build up in the blood and damage the developing brain.
- Staying on a low protein diet keeps Phe levels in a safe range, allowing for normal development and a healthy life.
- Eating the wrong foods will not make a person with PKU sick right away, but will cause problems over the long-term. Having food that is not part of the diet should not be considered a "treat" as it will have implications for an individual with PKU.
- A person with PKU does not outgrow it and must stay on the diet for life.

A Parent's Perspective

"Since there were many unannounced birthday cupcakes or cookies that we were not able to plan for, I kept a container of food items in my son's classroom that were in separate baggies. He could pick from these if he was unable to have the unannounced food. Each baggy had a label of the food item and then the teacher would send it home so I would know what he had."

You should let the following people know about your child's PKU:

- The preschool director, or the school principal
- The class teacher(s)
- Early drop-off or after-care supervisors and staff
- Any food service staff that might provide meals for your child
- A school nurse, if applicable

Changes in school or classroom practice or policy may also need to be made to help your child adhere to their diet, such as:

- Creating a "no-swapping" rule to prevent children from trading or sharing food.
- Asking teachers to pack any leftover food in your child's lunchbox so you can determine how much was eaten.
- Keeping low protein snacks at school when snacks or treats are necessary.
- Allowing child to drink formula at school or in the classroom.

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School-Provided Lunches

You can pack lunches and snacks from home for your child, but some parents and children prefer or need to use school-provided lunches.

Each preschool or school will vary in what it provides in terms of meals or cafeteria food. Regulations that require schools to provide school lunches for children with special dietary needs differ from state to state. Several federal regulations provide the legal basis for requiring schools to offer nutrition services to children with special needs. These include: The Rehabilitation Act of 1973, The Individuals with Disabilities Education Act (IDEA) of 1990, and the Americans with Disabilities Act of 1990³¹.

The Rehabilitation Act of 1973 mandates that students with disabilities not be excluded from any program which receives Federal Financial Assistance (section 504). Further, as part of the USDA's nondiscrimination regulation, federal law requires that schools make substitutions in foods for children considered to have a disability, and whose disability restricts their diet (7 CFR, Part 15b.3). Additionally, USDA regulation explains school requirements and specifies that schools must serve special meals at no extra charge to students whose disability restricts their diet (7 CFR, Part 15b.26(d))³².

This means that schools need to work with families to provide appropriate meals for children with special dietary needs; however, regulations do vary by state. Some states may only require that schools provide low-protein choices from their regular menus, while others may actually order special low-protein foods for your child's meal. You will need to learn the requirements for your state and work with your child's school to determine the menu for your child's school lunch.

For your child to receive a special school lunch, you may also need medical authorization or need to fill out an Individualized Education Plan (IEP). Talk to your child's school about these requirements.

Regardless of your child's school lunch policies, here are some helpful tips for working with the school to ensure your child receives the diet she needs³³:

- Get to know the Food Services Director and staff.
- Encourage them to contact you with questions about your child's diet.
- Limit the staff trained to prepare food for your child to one or two people.
- Ensure there is a good understanding of your child's special diet to avoid any mistakes in interpreting diet orders.

³¹ Cambrooke Foods. Low Protein School Lunch Program. Parents Guide.

³² Cambrooke Foods. Low Protein School Lunch Program. Parents Guide.

³³ Cambrooke Foods. Low Protein School Lunch Program. Parents Guide

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Packed Lunches

You may find that it's easier to pack lunches. Allowing your child to choose lunch options will make him or her happier with the choices and preparing a list of options in advance will make it easier for both of you. Some ideas for packed lunches are:

- Sandwiches made with low protein bread
 - o Vegetables sandwiches are delicious – try roasted vegetables for a tasty option
 - o Low protein cheese on its own or paired up with a variety of vegetables to change it up
 - o Low protein peanut butter and jelly sandwiches (remember to ask in advance if your child's school allows peanut butter as some schools are "nut free" due to allergies)
- Low protein pasta or rice can be brought in a thermos to keep it warm
- Make a fruit cocktail with a variety of fruits for a refreshing snack
- Cut up lots of vegetables in advance and keep them in the fridge for quick lunch snacks
- Other low protein snacks can be kept in stock for variety such as low protein chips, puddings or fruit cups

After-School Activities

A Parent's Perspective

"I have found that people are so willing to accommodate his needs if I let them know what they are."

Planning and preparation are needed if your child participates in after school activities. Parents can educate the after-school activity leader or coach about PKU and share that your child may need to take a break to drink formula or have a snack provided from home. Informing your child about the plan and ensuring that your child has extra formula or snacks

that are appropriate for the length and physical intensity of the activity can help promote a positive health outcome.

A Parent's Perspective

"We create a menu for our son that is based on the school lunch menu on a monthly basis. Our son's menu has on it everything he can eat that is on the regular menu with the appropriate measurements, as well as what his substitutions should be for the high Phe food."