SELF-MANAGEMENT STAGES

The chart below lists common tasks and ages at which children should be able to complete them. (Appropriate ages may be different for different families, but the general ages are probably the same.)

0-3 Years

Parents learn about food and nutrition Learns to drink from a cup, feed self Needs help getting dressed Needs help brushing teeth Understands simple sentences



4-6 Years

Parents continue to learn, teach child Can use utensils, feed self Needs help getting dressed Needs some help brushing teeth Begins to understand things like "yes foods" and "no foods"



7-10 Years

Understands "good eating habits" Can communicate well with parents Can get dressed without help Parents help child to choose nutritious foods Can prepare simple snacks and meals



11-15 Years

Becomes more responsible for health: food choices, exercise Develops sense of independence Parents provide nutritious foods Can prepare simple snacks and meals Takes on new responsibilities

16-18 Years

Can plan for future events: meals, outings Chooses a variety of healthy foods Takes on new challenges Responsible for healthy behaviors





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SELF-MANAGEMENT QUIZ

Learning to manage PKU requires skills that come with age. For example, you wouldn't expect a 3 year old to make his own formula. Some PKU management skills are listed below. Decide what age goes with each skill.

(Skills develop at different ages, and some skills are more important for some people to learn than others, so you may have learned things at different ages.)

- 1. Parents learn what PKU is.
 - a. Child is 0-3 years old
 - b. Child is 4-6 years old
 - c. Child is 7-10 years old
- 2. Child begins to make formula independently (with parent supervision)
 - a. 4-6 years
 - b. 7-10 years
 - c. 11-15 years
- 3. Child learns about "yes" and "no" foods, and learns to count.
 - a. 0-3 years
 - b. 4-6 years
 - c. 7-10 years
- 4. Child makes transition to the adult clinic.
 - a. 6 years
 - b. 12 years
 - c. 18 years
- 5. Child begins learning to plan menus.
 - a. 0-3 years
 - b. 4-6 years
 - c. 11-15 years
- 6. Child can do Guthrie independently.
 - a. 4-6 years
 - b. 7-10 years
 - c. 15-17 years
- 7. Child can give a brief explanation of PKU to friends.
 - a. 0-3 years
 - b. 4-6 years
 - c. 15-17 years
- 8. Child can pack school lunch.
 - a. 4-6 years
 - b. 7-10 years
 - c. 11-15 years
- 9. Parents introduce finger foods and cup to child.
 - a. 0-3 years
 - b. 4-6 years
 - c. 7-10 years
- 10. Child is responsible for remembering recent blood levels.
 - a. 4-6 years
 - b. 7-10 years
 - c. 15-17 years

Can you think of other skills that you need to manage PKU? When would you expect to learn them?











Tasks that 10-18 year olds should complete are listed below with approximate ages:

10-12 years

- Begin to prepare and consume formula independently each day (with help from parents)
- Prepare simple entrees independently
- Know what blood levels are ideal

13-14 years

- Increase self-monitoring (with parent support) in formula preparation and consumption
- Independently manage total phe intake for the day
- Learn menu planning
- Complete food records

15-17 years

- Responsible for all aspects of self-management
- Able to do Guthrie
- Able to explain basics of PKU—"What is it?"
- Responsible for remembering recent blood levels

18 years

- Transition to adult-based clinic care
- Ready to live independently, including:
- Formula preparation and consumption Food preparation and records Monthly serum phe









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