

An important part being a parent with a child who has HCU is helping yourself and your child manage HCU successfully. The self-management timeline supplies an overview of what to expect as your child becomes more independent in managing their care. This flexible guide suggests a gradual release with age appropriate goals to make this happen.

Homocystinuria (HCU) Self-Management Timeline

Age	Tasks
0-6 months	<ul style="list-style-type: none"> • Parents learn about and adjust to HCU
6-7 months	<ul style="list-style-type: none"> • Parents start to offer low-protein solid foods • Introduce cup with water
8-9 months	<ul style="list-style-type: none"> • Parents introduce finger foods
10-15 months	<ul style="list-style-type: none"> • Parents consider final weaning from bottle (discuss transition with your clinic)
2-3 years	<ul style="list-style-type: none"> • Learn the concept of “formula first” • Learn to distinguish “yes” and “no” foods • Transition from infant formula to child/adult formula
4-5 years	<ul style="list-style-type: none"> • Start learning how to count foods - “how many” • Start learning how to use a scale – “how much”
5-6 years	<ul style="list-style-type: none"> • Help with formula preparation • Learn how to deal with other’s curiosity about HCU
7-10 years	<ul style="list-style-type: none"> • Prepare formula with decreasing supervision • Choose after school snack • Learn to pack school lunch • Begin to list foods on food record • Begin weighing food regularly on scale
10-12 years	<ul style="list-style-type: none"> • Begin to prepare and consume formula independently each day (with parental monitoring)
13-14 years	<ul style="list-style-type: none"> • Increasing self-monitoring (with continued parent support) in formula preparation and consumption • Independently manage total protein/met intake for the day • Learn menu planning • Responsible for food records
15-17 years	<ul style="list-style-type: none"> • Competent to perform and primarily responsible for all aspects of self-management with continued parent support • Able to schedule blood draw • Able to explain the basics of HCU – “What is it?” • Responsible for remembering recent blood levels
18 years	<ul style="list-style-type: none"> • Transition to adult-based clinic care • Ready to live independently, including: <ul style="list-style-type: none"> ○ Formula preparation and consumption ○ Food preparation and records ○ Setting and keeping own appointments on regular basis • Parents act as consultants

Adapted from: University of Washington University. *PKU and the Self-Management Timeline* [PDF file]. Retrieved from <https://depts.washington.edu/pku/pdfs/selfmanagetmln.pdf>