

What is HCU?

Homocystinuria (Ho-mo-cys-tin-uria), or HCU, is a rare inherited metabolic condition. People with HCU cannot break down the amino acids methionine (me-**thahy**-uh-noon) and homocysteine (hō-mō-'si-stē-, ēn) in their bodies. Methionine (Met) is found in most foods that contain protein. HCU is a severe medical condition that can be treated with a special HCU medical formula, a diet low in protein and Met, and some vitamins and other medicines.

What happens?

Normally Methionine breaks down into another amino acid, homocysteine (HCY) (hō-mō-'si-stē-, ēn). The byproduct homocysteine (HCY) also builds up and has very unhealthy and dangerous side effects when protein (more specifically Met) is ingested. High HCY levels is harmful to the eyes, skeletal, vascular and central nervous systems.

High HCY levels may cause:

- Severe nearsightedness
- Lens dislocation
- Cognitive deficits
- Behavioral problems
- Clumsiness
- Long limbs
- Blood clots
- Strokes

To help prevent these issues, those with HCU must follow a special diet with low protein and drink their HCU formula throughout the day.

How can I help?

Teach your student as you would anyone else. HCY levels can fluctuate. Your student with HCU may need additional time or attention to keep pace with the classroom.

Help to ensure your student drinks their HCU formula. Peer pressure may cause children to secretly empty or hide formula. It is important your student has a place they feel safe storing and consuming their formula.

Communicate with parents and ask questions. Since you spend a fair amount of time with your student, you may be the first to notice issues related to HCU. Successful HCU management will rely on both parents and school staff communicating with each other.






Classroom Celebrations

Although your student with HCU cannot have store bought cupcakes, cookies or cake, there are low protein versions of these treats. Be sure to let parents and cafeteria staff know about an upcoming celebration so they can provide an alternative snack. A stash of shelf-stable treats may want to be kept in the classroom for unexpected celebrations.



HCU formula is an essential part of the diet. Since those with HCU cannot have many foods that contain whole protein, they rely on HCU formula to supply Met free protein. HCU formula is typically consumed a few times a day.

Helpful Tips

-  Encourage diet adherence. "Just a bite" is highly discouraged with a low protein diet. Let parents know if their child doesn't eat foods that are sent from home or if they eat anything that was not sent from home or agreed upon in advance.
-  Treat them the same as your other students. Your student is not sick and shouldn't be treated as such. If they follow the diet they can be just as successful as their classmates.
-  Do not let HCU define your student. Establishing a sense of self outside of HCU is a crucial part of self acceptance.

Educational Accommodations

Children with HCU may experience challenges at school. These plans are available to make sure they have the best chance of succeeding in the classroom.

Section 504 Plan:

A Section 504 Plan assists in establishing accommodations that help safeguard and ensure that a child with HCU has the same learning opportunities as other students in the classroom.

Individual Education Plan (IEP):

An IEP is a written statement of an educational program designed to meet a child's individual needs. An IEP sets reasonable and attainable learning goals for a child with HCU.

Accommodations might include:

- ⇒ Preferential seating
- ⇒ Modified textbooks or audio-visual materials
- ⇒ Oral test and visual aids
- ⇒ Providing low-Met or Met-Free protein foods in the school cafeteria
- ⇒ Allowing a child with HCU to keep their low-Met formula at their desk



Nutritional Accommodations



If your school receives funding under the National School Lunch program, the school is required to make accommodations for their special dietary needs. Low protein diets are not easily accommodated using only conventional foods and for this reason, low protein food companies exist. Please visit the following link to learn about Cambrooke Therapeutics school lunch program:

https://www.cambrooke.com/included/docs/foodservicesguide_summary.pdf

| Not Allowed (Not allowed unless okayed by parent) | Limited Amounts (Allowed, but in limited quantities) | Permitted (May still need to be counted) |
|---|---|--|
| <ul style="list-style-type: none"> ⇒ Meat ⇒ Most Dairy ⇒ Eggs ⇒ Beans ⇒ Legumes ⇒ Nuts ⇒ Most grains | <ul style="list-style-type: none"> ⇒ Veggies: Corn, Peas, Brussel Sprouts, Potatoes ⇒ Fruit: Kiwi, Avocado, Figs, Jackfruit, Oranges ⇒ Sugary Cereals ⇒ Potato Chips ⇒ Popcorn | <ul style="list-style-type: none"> ⇒ Veggies: celery, cabbage, bell peppers, tomatoes, eggplant ⇒ Fruits: Apples, Papaya, Pears, Strawberries, Tangerines ⇒ Butter, Oils ⇒ Medical Low Protein Foods |

This information is not intended to take the place of medical advice or care you receive from your health care professional and intended for information purposes only. Permitted foods and quantities will vary. For a full list of permitted foods, please consult the child's metabolic care team.