



Guide to HCU (Homocystinuria)

Teachers & School Nurses

What is HCU?

HCU is short for Homocystinuria (ho-mo-sis-tin-ur-ee-a), which is an inherited metabolic condition. People with HCU cannot break down the amino acid methionine in their bodies. Methionine (MET) is found in all food that contains protein. HCU is a serious medical condition that is managed with a special HCU formula, a diet low in whole protein and MET as well as certain medications.

What happens?

Since people with HCU cannot break down MET, too much whole protein in their diet will cause an unhealthy and dangerous build up of MET and homocysteine (HCY) in their bodies. If not managed properly, HCU can lead to intellectual disabilities, eye and skeletal issues, as well as vascular problems.

Poorly managed HCU may lead to:

- Developmental delays
- Intellectual disabilities
- Thromboembolic disease
- Heart disease
- Long limbs
- Osteoporosis
- Retinal detachment
- Ectopia lentis

To help prevent this many individuals with HCU must follow a special diet low in whole protein, drink their HCU formula throughout the day and take certain medications.

What should I do?

Teach your student as you would anyone else. Some students with HCU may need additional time or attention to keep pace with the classroom.

Help to make sure your student drinks their HCU formula. Peer pressure may cause children to secretly pour out or hide formula. It is important your student has a safe place to consume and store the formula.

Communicate openly with parents and ask questions. Since you spend a good portion of the day with your student, you may be the first to notice HCU-related problems. Bringing this to the parents' attention quickly is very important for successful HCU management.



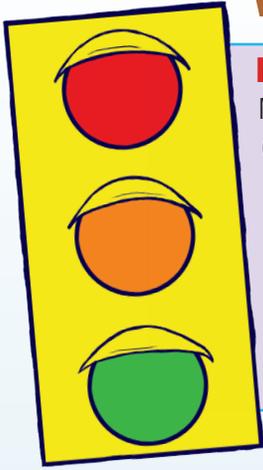
HCU formula is a critical part of the diet. Since someone with HCU cannot have many foods that contain whole protein, they rely on HCU formula to supply special protein. HCU formula is typically consumed 3-4 times per day.



Helpful Tips

- ✓ Always encourage diet adherence. "Just a taste" can set a bad example that not following the diet at school is acceptable behavior.
- ✓ Treat this child the same as other students. Support their diet, formula and medication needs to help them be as successful as the rest of the class.
- ✓ Do not let HCU identify your student. Helping to establish a sense of self outside of HCU is a lesson your student will remember for life.

What can they have?*



NOT PERMITTED

Meat, poultry, fish, eggs, nuts, peanut butter, seeds, regular bread, pasta, rice, grains, beans, milk, yogurt, cheese (other dairy) and soy/pea protein-based meat alternatives.

PERMITTED IN LIMITED AND MEASURED AMOUNTS

Fruit juice, rice milk, butter, starchy vegetables such as peas, corn and potatoes.

PERMITTED LOW PROTEIN FOODS

Special foods made to be low in protein, such as low protein breads, pastas and baking mixes. Many fruits and vegetables, dairy-free margarine, cooking oils and many sugar-based sweets (such as lollipops and jelly beans).

*This is not a complete list. Permitted foods and quantities will vary. Always consult the metabolic clinic prior to making any changes to the HCU diet plan. To find out the protein content of food, visit HowMuchPHE.org or MetabolicDietApp.org

Classroom Birthdays



Although your student with HCU may not be able to have regular cake, cookies or cupcakes, there are low protein versions of these fun treats. Be sure to let parents and cafeteria staff know about an upcoming celebration so they can provide an alternative snack.



Resources

To learn more about HCU and the diet, visit:

HCU Network America- www.hcunetworkamerica.org

HCU Network America is a non-profit organization whose mission is to help patients with HCU and related disorders manage their disease and to find a cure.

Nutricia – www.NutriciaMetabolics.com

Learn more about HCU and other metabolic disorders in our dedicated education section and our informative blog.

The information contained in this educational material is for information purposes only and is not intended to replace medical advice from a metabolic healthcare professional. Health-related decisions should be made in partnership with a qualified healthcare provider. This material is not intended to be a substitute for professional medical advice, diagnosis or treatment.

HCU DIET PLAN



_____ drinks _____ fl oz of HCU formulat at school

Parent Contact Information

The best way to reach me is by (circle one):

Phone

Email

Parent Name: _____

Phone: _____

Email: _____

Notes: _____

FACT

HCU is a medical diagnosis included in the Rehabilitation Act (section 504) and the Americans with Disabilities Act. All federally funded school lunch programs are required to provide a low protein option for children with HCU.