

# Caretakers Guide to HCU



## 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.

## Cause and Effect

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 are harmful to the eyes, skeletal, vascular and central nervous systems.



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



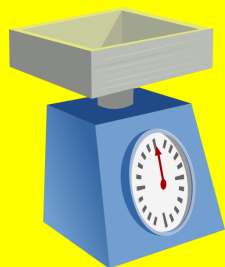
To help prevent these issues, those with HCU must follow a special diet with low protein and drink their HCU formula throughout the day.

**What is a low protein diet?** The majority of the HCU diet is composed of fruits, vegetables and specialty low protein foods.



**Permitted:** May still need to be counted

- ∂ Fruit: Apples, Papaya, Pears, Strawberries, Tangerines
- ∂ Veggies: Bell Peppers, Cabbage, Celery, Eggplant, Tomatoes
- ∂ Butter and Oils
- ∂ Medical Low Protein Food



**Limited Amounts:** Allowed, but in limited quantities

- ∂ Veggies: Brussel Sprouts, Corn, Peas, Potatoes
- ∂ Fruit: Avocado, Figs, Jackfruit, Kiwi, Oranges
- ∂ (Some) Sugary Cereal
- ∂ Popcorn

**Not Allowed:** Not allowed unless okayed by parent

- ∂ Meat
- ∂ Nuts
- ∂ Grains
- ∂ Most Dairy
- ∂ Beans
- ∂ Eggs
- ∂ Legumes

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.



**HCU Network America**

To learn more about Homocystinuria, please visit: <https://hcunetworkamerica.org>

## Support

- ♥ Treat them as any other child
- ♥ Teach them following the diet is important
- ♥ Encourage them to drink their formula
  - ♥ Don't make comments about the smell or flavor
- ♥ Don't deviate from the allowed foods, even if it's "just a bite"
- ♥ Attend homocystinuria events



## Communicate

- Communicate with parents and ask questions
- Communicate what they have eaten, have not eaten, or if you plan to feed them anything—ask in advance. Make sure the items you have selected fit their protein allowance.



## Remember

- They are not sick
- It's not an allergy. You will not see immediate side effects if the diet isn't followed
- Damage from not following the diet tends to be irreversible

• It's a diet for life!

## Learn

- ∂ Learn to properly read food labels
- ∂ What foods they can and cannot eat and their exact protein and methionine contents.
- ∂ Learn how to weigh and measure foods
- ∂ Learn how to cook low protein foods
- ∂ Learn how to make their formula
- ∂ Learn more about Homocystinuria

