

## Let's Talk About...

# Hemolytic uremic syndrome (HUS)

Hemolytic (hee-mo-LIT-ik) uremic (yoo-REE-mik) syndrome, or HUS, is a rare disorder that affects children, most often younger than 5 years old. HUS outbreaks usually happen during the summer months. Children who have HUS have stomach pain, vomiting, and severe, bloody diarrhea. Even after the vomiting and diarrhea stop, they may still be pale, tired and irritable.

### What causes HUS?

Most often, HUS is caused by eating food contaminated with E. Coli bacteria. We all have many forms of E. Coli in our digestive tract, but some rare forms of the bacteria are much worse than others. One form of E. Coli infects the intestines and makes a poison, which gets into the blood.

Blood flows to the kidneys, which filter waste materials and extra fluids from the blood — creating urine. Poison clogs small blood vessels in the kidneys. Red blood cells are damaged as they try to squeeze through the clogged blood vessels. The kidneys have to work harder to remove wastes and extra fluid from the body and may stop working well. The kidneys may not make as much urine.

If the kidneys don't work well, fluid stays in the body and can cause high blood pressure. It can also pool in different places, often the hands and feet and cause swelling called edema (ed-EE-ma).

### How is HUS treated?

Your child will be hospitalized until their kidneys improve, they are eating well, and they have adequate nutrition. The average hospital stay is 10–14 days, depending on how serious the disease is. Your child's healthcare providers will watch carefully to help your child get well. They will put a tiny tube, called an IV catheter, into your child's vein to give fluids and medication.



Your child's healthcare providers will:

- Check that your child has enough fluids in their system
- Make sure the kidneys are working
- Replace blood if needed
- Manage high blood pressure
- Help control possible seizures
- Give your child proper nutrition

### Fluids

Your child will get fluids through an IV catheter. The amount of fluid will be balanced so they will have the right amount of salts and water.

### Blood replacement

Infants and children with HUS lose lots of red blood cells. This condition is called anemia (ah-NEE-mee-a). Your child's red blood cell count will be watched carefully. If it is low, they may be given more red blood cells. This process is called a blood transfusion. Most children only need to receive a few transfusions.

## Blood pressure management

Half of the children with HUS get high blood pressure. It usually comes and goes. Your child's blood pressure will be checked often. If needed, your child will take medicine to lower their blood pressure.

## Nutrition

When your child is feeling better, a dietitian will help them maintain a healthy diet. Not eating well will lead to poor nutrition. Poor nutrition can lead to more infections and complications.

## Total parenteral nutrition (TPN)

Your child will receive liquid nutrients (called TPN) through an IV if they can't eat enough food to maintain adequate nutrition.

## Nasogastric (NG) tube

If your child's digestive system is not working well enough, they may need to receive food through a nasogastric (NG) tube. This tube is put into the nose and guided to the stomach.

When your child stops vomiting and no longer has diarrhea, a dietitian will design a diet that is best for your child. A special diet will be important after your child leaves the hospital.

## Seizure control

Seizures may occur in a very small number of HUS patients. If your child does have a seizure, their healthcare provider will give them anti-seizure medication.

## Dialysis

If your child's kidneys do not work, they will need dialysis. This is a process that removes waste from the bloodstream. Your child's healthcare provider will discuss it further with you if your child needs dialysis.

## Medicines and care after the hospital

After leaving the hospital, your child will visit the outpatient nephrology clinic for more care. The clinic staff will carefully watch your child's condition.

At home, your child may need medicines to control seizures and high blood pressure. Lab tests will be done to watch how well your child's kidneys work and if their fluids are balanced. Healthcare providers will check your child's blood for salt, nutrient, and waste levels.

Call your healthcare provider if your child:

- Looks very pale
- Has a bad headache
- Has nausea or is vomiting
- Has blurry vision

## Notes

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