

Haemolytic uraemic syndrome (HUS) (Overview)

This infoKID topic is for parents and carers about children's kidney conditions.

This leaflet has the overview only.

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In haemolytic uraemic syndrome (HUS), the small blood vessels inside the kidneys are damaged. There are changes in the blood and the kidneys stop working as well as they should. There are different types of HUS – the most common is called STEC-HUS (or VTEC-HUS).

STEC-HUS happens in a few children after a tummy infection caused by bacteria (germs) called *E. coli*. The tummy infection causes diarrhoea, feeling sick or being sick, and sometimes blood in the stool (poo).

The small number of children who get STEC-HUS after this infection usually get very ill, and need to be admitted to hospital for monitoring and treatment. They may feel weak and tired, look pale and/or get tiny pink or purple spots on their skin. They may not pass urine (wee) as much as normal, and may have swelling in their body. STEC-HUS can lead to other complications that will need treatment.

Most children fully recover from this STEC-HUS, and it does not come back. Some children will have long-term problems with their kidneys, and in serious cases will need long-term specialist care.



About the urinary system and urine

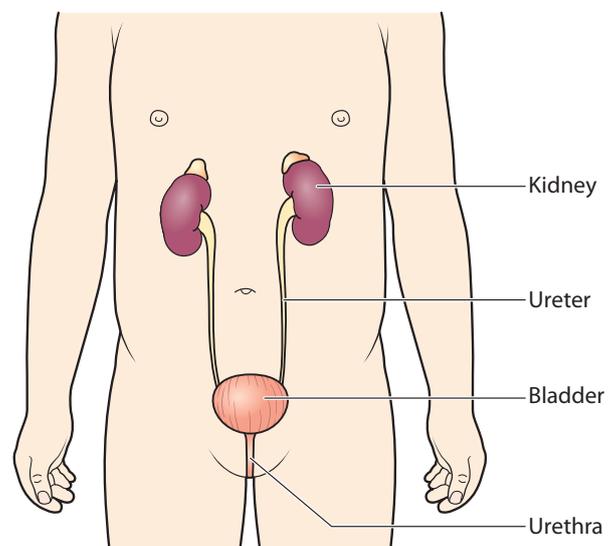
The **urinary system** gets rid of things that the body no longer needs, so that we can grow and stay healthy.

The **kidneys** are bean-shaped organs. They filter blood to remove extra water and waste products in urine (wee). Most of us have two kidneys. They are on either side of our spine (backbone), near the bottom edge of our ribs at the back.

The two **ureters** are long tubes that carry urine from the kidneys to the bladder.

The **bladder** is a bag that stores urine until we are ready to urinate. It sits low down in the pelvis.

The urethra is a tube that carries urine from the bladder to the **outside** of the body.



» [More about the urinary system and kidneys](#)

Symptoms and complications

Symptoms and signs of gastroenteritis

STEC-HUS happens after a tummy infection, **gastroenteritis**. This causes the following:

- diarrhoea for several days
- feeling sick (nausea), being sick (vomiting) or tummy pain
- fever (temperature above 38°C) – some children may sweat and/or seem shivery
- sometimes, blood in the stool (poo), which may start a few days after children first get diarrhoea – **if your child has blood in his or her stool, take him or her to your family doctor.**

→ **Infections can spread very easily. Your doctor may ask you to take your child out of school or nursery to avoid passing it on to other children.**

Symptoms and signs of STEC-HUS

Children who get STEC-HUS after this infection may have the following:

- urinating (weeing) less often, passing smaller amounts, or sometimes not urinating at all
- feeling weak and tired
- looking pale – occasionally there are tiny pink or purple spots on their skin
- swelling of the body (**oedema**), especially around their eyes or legs and feet
- headache.

Complications – kidneys

The kidneys do not work as well as normal in this disease. This may lead to **acute kidney injury (AKI)** – when the kidneys suddenly fail or stop working properly – and some of these children need special treatment. STEC-HUS may also lead to high blood pressure (**hypertension**), which may cause headaches, vomiting or blurred (fuzzy) vision.

Other complications

Sometimes STEC-HUS can cause serious complications in other parts of the body, though these are more rare. They include:

- a higher amount of blood sugar, which may lead to **diabetes** – this is usually temporary
- **colitis** – when the colon (bowel) gets inflamed, and may lead to tummy pain or cramps – a few children are unable to eat normally and need special feeds and, occasionally, surgery
- seizures (convulsions or fits), problems with vision, or paralysis (when part of the body cannot move) – this is called **cerebral HUS** and is very rare.

Causes

E. coli

The tummy infection is caused by germs (bacteria) called *Escherichia coli*, or *E. coli*. Both children and adults can become infected by *E. coli* by being in contact with the faeces (poo) of animals that carry *E. coli*. The infection can also spread from person to person.

There are many strains, or types, of *E. coli* – one type that is more dangerous, and may lead to HUS, is called *E. coli* O157.

STEC

E. coli O157 (and occasionally other types of *E. coli*) sometimes make toxins (like poisons) that are called shiga toxins. These are called **shiga-toxin-producing E. coli (STEC)**. (The toxins may also be called verocytotoxin, and the bacteria called **verocytotoxin-producing E. coli (VTEC)**.)

Most people get better after a tummy infection. However, a few people who are infected by STEC develop STEC-HUS.

This kind of HUS used to be called D+ HUS (the D stands for diarrhoea) or 'typical' HUS.

How the infection happens

The most common source of STEC in the UK is cattle, though the bacteria have also been found in faeces of other animals, including deer, rabbits, horses, pigs and wild birds.

People can become infected by:

- eating food that is contaminated with faeces
- contact with infected animals, either directly or through inadvertent contact with animal faeces (for example at farms, petting farms and campsites);
- contact with other people who have the illness (i.e. through inadequate hand hygiene after using the toilet and/or before food handling, particularly in households, nurseries and infant schools)
- drinking water from inadequately treated water supplies
- swimming or playing in contaminated water, such as ponds or streams.

Test and diagnosis

Your child's doctor will talk to you or your child about his or her symptoms and any medicines that he or she takes, and do an examination. Your doctor can **diagnose** (identify) STEC-HUS after some tests, such as a **urine test, blood test** and stool test.

Telling the local health protection unit

If your doctor thinks that your child has a STEC infection – even if he or she does not develop HUS – your clinic or hospital will inform your local health protection unit. A public health officer may speak with you to find out how your child might have been infected. This will help prevent the infection from spreading.

Treatment

Where will my child be treated?

Your child will probably need to stay in hospital for a few days or a few weeks. A team of healthcare professionals will monitor your child to check how well his or her kidneys are working, test how much he or she is urinating (weeing), and measure his or her blood pressure. They will support you and your family throughout the treatment.

Any child admitted to hospital with diarrhoea will be cared for in isolation (without other patients around). This reduces the risk of passing on the infection to other people.

What does treatment do?

Many children with STEC-HUS will not need special treatment, but will be carefully monitored to make sure they have the right amounts of water, salts and minerals in their body. Some children need to make temporary changes to what they eat and drink, and may need a feeding device to make sure they get the nutrients they need.

Some children will need treatment for complications. This may include medicines, a **blood transfusion** or, more rarely, surgery.

The kidneys do not work as well as normal during this illness. In some children, this is more serious and they will need dialysis, which uses special equipment to remove waste products and extra water and salts from their body.

Prevention

You can help prevent a STEC infection by doing the following:

- make sure you and your children wash your hands thoroughly using water and soap, especially after visiting a farm or having contact with animals, after going to the toilet, after handling raw meat and before eating
- use separate chopping boards and kitchen utensils for raw and cooked meat, and make sure that meat is cooked right through
- wash fruit and vegetables before cooking or eating.
- Family members who might have been infected by STEC also need to take care to avoid passing on the infection. If they work in food preparation, health care or child care, they will need to stay off work until the symptoms have settled.

→ **If your child has HUS, it is important to wash your hands very carefully, especially after changing or touching nappies or soiled clothes. This will help prevent the infection from spreading to other members of the family.**

About the future

Will my child get better?

Many children with STEC-HUS get better after a few weeks. Some children will have more serious complications that need treatment.

There is a small risk of death with reports indicating that less than 2 children in 100 with STEC-HUS die. This can happen during the acute phase of the illness.

Follow-up

All children who have STEC-HUS need to go back to the hospital or clinic for follow-up appointments, sometimes for years after the illness. These check for any health problems, including with their kidneys.

Long-term effects

About 3 in 10 children will have long-term problems with their kidneys. These children may need further care. They will need to go back to the hospital or clinic for regular follow-up appointments.

Occasionally, STEC-HUS can lead to long-term problems in other parts of the body, including the gut or the central nervous system (including the brain).

Acknowledgements

This leaflet was co-authored with:

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» **More information about HUS on www.infoKID.org.uk**

Your notes and contact information

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