

Haemolytic uraemic syndrome (HUS)

This infoKID topic is for parents and carers about children's kidney conditions. Visit www.infoKID.org.uk to find more topics about conditions, tests & diagnosis, treatments and supporting information.

Each topic starts with an overview followed by several sections with more information.

[Links to sections](#) in topic | [Other topics](#) available on website

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.



Overview

About the urinary system and urine

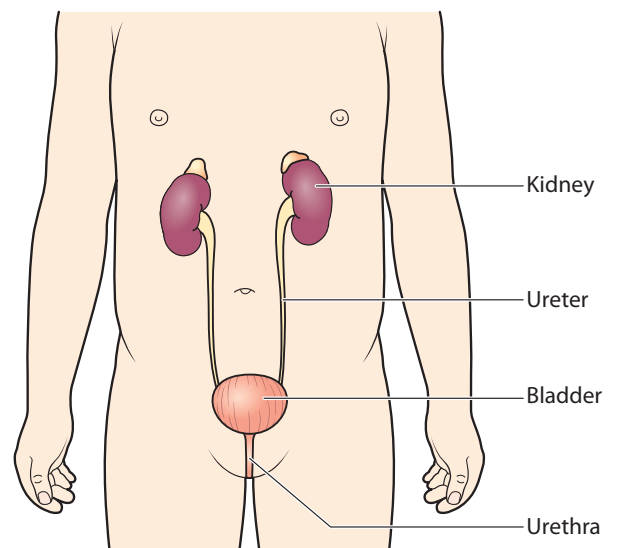
The **urinary system** gets rid of things that the body no longer needs, so that we can grow and stay healthy.

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.

» **More about symptoms and complications**

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.

» **More about causes**

» **More about how I can avoid being infected**

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.

» [More about tests and diagnosis](#)

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.

» [More about treatment](#)

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.**

» [More about prevention](#)

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).

» [More information about the future](#)

Acknowledgements

This leaflet was co-authored with:

- Aiofe Waters (Lead) and members of the Rare Renal Disease Group for STEC HUS
- Members of Risk Assessment and Response, Department of Gastrointestinal, Emerging & Zoonotic Infections, Health Protection Services Colindale.

Symptoms and complications

Symptoms and signs of gastroenteritis

STEC-HUS happens in a few children after they have gastroenteritis, an infection in the tummy (or gut) that is caused by shiga-toxin-producing *E. coli* (STEC).

Symptoms and signs include:

- 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

Most children recover from gastroenteritis. In a few children, the infection triggers STEC-HUS. Some children have the following symptoms:

- urinating (weeing) less often, passing smaller amounts of urine, or, sometimes, not urinating at all
- feeling weak and tired, and sometimes looking paler than usual – caused by a drop in the amount of **red blood cells** or **haemoglobin**, a substance in red blood cells, which normally carry oxygen round the body (**anaemia**)
- occasionally, tiny pink or purple spots on their skin – caused by a drop in the amount of **platelets**, blood cells that help the body to heal (**thrombocytopenia**).

Complications

Some children have complications, more serious health problems.

→ Your child's healthcare team will carefully check for complications. They will talk about the treatment options with you.

Kidneys

The kidneys do not work as well as normal in this disease – we say there is reduced kidney function.

Many children will go into **acute kidney injury (AKI)** – when the kidneys suddenly fail or stop working properly. This is measured with a **blood test** – when there is too much of a waste product called creatinine, which is normally removed by the kidneys in urine. HUS is the most

common cause of AKI in children. Some children with AKI need to take medicines or have more intensive treatment such as **dialysis**, which uses special equipment to remove wastes and extra water and salts from the body. Children with AKI may have the following:

- blood pressure that is too high (**hypertension**) – this may cause headaches, vomiting or blurred (fuzzy) vision; blood pressure can be controlled by changes to the diet or, sometimes, medicines
- swelling or puffiness in their body (**oedema**), especially around their eyes or legs and feet – this happens when their kidneys cannot remove enough salt and water from their body in urine
- feeling breathless – this happens when fluid builds up in the area around their lungs.

Blood sugar

A small number of children with HUS get high levels of sugar in their blood. This happens when the **pancreas**, which makes and releases chemicals that break down food, becomes inflamed – this is called **pancreatitis**. This may cause burning pain in the tummy and back, nausea and vomiting.

The pancreas makes the hormone **insulin**, which controls the level of sugar in the blood. If it is inflamed, it cannot make enough insulin, and this may lead to acute **diabetes**, when the body has too much sugar. Children will need to be given insulin by injection. It is usually temporary, but children need follow-up.

Bowel

The *E. coli* infection that causes STEC-HUS affects the colon (large intestine, or part of the bowel). Some children get **colitis** – when the colon becomes inflamed and irritated. Children may get tummy pain or cramps, may have stomach pain and may feel tired. Some children cannot eat normally – they may need to get nutrition into their blood using a plastic tube in a vein. Occasionally, surgery is needed.

Central nervous system, including brain

Rarely, HUS affects the central nervous system, including the spine and brain – this is called **cerebral HUS**. This can lead to:

- seizures – also called convulsions or fits
- problems with vision
- very occasionally, paralysis – when part of the body is unable to move.

What causes STEC-HUS?

STEC-HUS happens in a few children after they get gastroenteritis, an infection in their tummy or gut. This infection is usually caused by a particular germ, a bacterium called *Escherichia coli* O157, which is often shortened to *E. coli* O157.

Most children recover from gastroenteritis caused by these bacteria. In a few children, the infection causes HUS.

About *E. coli*

E. coli is a type of bacterium that is often found in the guts of animals, including cattle, sheep, deer and goats, and sometimes pets and birds. *E. coli* does not make the animal ill.

However, some strains, or types, can cause illness in humans. People may be infected with *E. coli* O157 by eating food that has been contaminated with the bacteria (usually because it has been contaminated with the animal's faeces, or poo).

About STEC

Some strains of *E. coli* make toxins, which are like poisons, that can cause serious illness. One toxin is called shiga toxin – the bacteria is called **shiga-toxin-producing *E. coli* (STEC)**. (It may also be called **verocytotoxin-producing *E. coli* (VTEC)**, but we will use STEC in this topic.)

The most common strain of *E. coli* that may cause HUS is ***E. coli* O157**.

» [Read more on the next page](#)

Who can get STEC-HUS?

For every 100 children who get a STEC infection, about 10 will develop HUS. Often, we see STEC-HUS after an **outbreak**, which means that a large number of people get infected with *E. coli*.

Only a small number of STEC are needed to cause illness. This means that the infection can spread quickly and easily within the family and in other settings such as nurseries, primary schools, nursing homes and hospitals.

What happens in HUS

In HUS, there is damage in the small blood vessels of the kidneys.

Blood cells

When the body tries to repair the damage, this causes problems with some **blood cells**, the living parts of blood.

- **Platelets** move to the areas that have been damaged, and clump together. They partly or completely block the blood vessels. This also means that there are fewer platelets going around the bloodstream.

- **Red blood cells**, which carry oxygen round the body, try to pass through the blocked blood vessels. They are broken up into little pieces.

» [Read more on the next page](#)

Kidneys

The kidneys stop working as well as they should. Children may urinate (wee) less or not at all. Water, salt and waste build up in the body.

» [Read more on the next page](#)

Other causes of HUS

Pneumococcal HUS

HUS may also happen after chest infections or meningitis (a disease in the area around the brain and spinal cord) caused by **pneumococcal** bacteria. This causes **pneumococcal HUS**. In serious cases, this can lead to complications with the brain.

Most children with pneumococcal HUS will need to stay in hospital for monitoring and treatment. They will need to take **antibiotics**, medicines that kill the bacteria. As the infection is treated, the HUS should go away.

Other infections and other causes

Other bacteria and some viruses can also sometimes lead to HUS. HUS can occasionally be caused by some medicines, or linked to other diseases.

Atypical HUS

Atypical HUS is a rare type of HUS that is not caused by an infection, but rather is thought to be linked to **genes**. It may run in families.

Some children with atypical HUS have diarrhoea, but this is not usually related to a STEC infection. This type of HUS tends to keep coming back, and is more likely to lead to long-term problems with the kidneys.

Causes: Read more about STEC

Shiga toxin damages the lining of **blood vessels** in the body. This usually happens in the intestines (gut), causing a tummy upset, including diarrhoea and sometimes blood in the stool (poo). In some cases, it can affect the kidneys, causing HUS.

Each year, between 800 and 1000 cases of STEC infection are reported by doctors in England. Compared to other bacteria, such as *Salmonella* or *Campylobacter*, which also cause tummy bugs, STEC infection is rare. However, doctors take STEC infections very seriously because the disease can be fatal (cause death), particularly in infants, young children and the elderly.

The highest numbers of cases are seen in children aged under 9 years of age and the number of cases is slightly higher in females across most age groups.

Causes: Read more about what happens to blood cells in HUS

In HUS, the body breaks down and destroys blood cells. The term '**haemolytic**' is used because 'haem' means blood, and 'lytic' means to break down. This is what happens:

- The cells that line the small blood vessels in the kidney filters (**glomeruli**) are damaged.
- The body tries to repair this by bringing in blood cells called platelets. Platelets form clots, or clump together, at places where there is damage. These clots partly or completely block the flow of blood.
- The platelets are used up trying to repair damage in the small blood vessels. This leads to a lower level of platelets in the rest of the blood, which is called **thrombocytopenia**. This can cause tiny pink spots on the skin and easy bruising.
- Red blood cells are broken up into little pieces as they pass through the narrowed blood vessels. This causes **haemolytic anaemia**. Because red blood cells carry oxygen round the body (in a substance called **haemoglobin**), a reduction in the number of these cells can cause children to feel weak and tired and look pale.

Causes: Read more about how the kidney works and what happens in HUS

How the kidney works

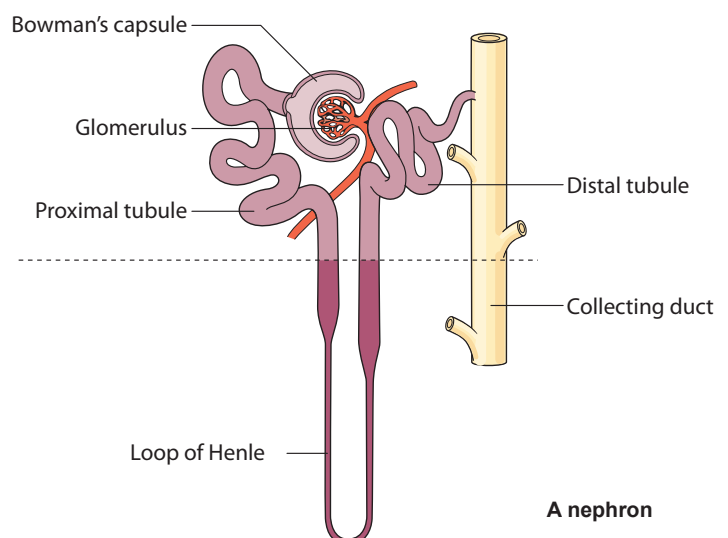
Inside each kidney, there are about one million **nephrons**. Each nephron is made up of a **glomerulus** (when we talk about more than one glomerulus, we say glomeruli), and a **renal tubule**.

- Each glomerulus acts like a sieve, helping to remove extra water and waste from the body, and holding on to blood cells and protein, which the body needs.
- Blood flows into the kidneys and to each glomerulus.
- Most of the water and some other substances in the blood pass through the glomeruli.
- This liquid flows into the renal tubule. Most of this liquid moves back into the bloodstream. The rest of it becomes urine.
- The urine leaves the kidney by the ureters and goes into the bladder, where it is stored until we are ready to go to the toilet.

» **More about what the kidney does**

What happens in HUS

The blood clumps together and forms clots in the glomeruli. The glomeruli cannot filter blood as well as usual. The kidneys makes less or no urine, and water, salt and waste build up in the body, leading to swelling. The word **uraemic** means a build-up of waste in the body.



Tests and diagnosis

Your child will need some tests to diagnose (or identify) STEC-HUS and find out the best treatment. Your child will need an examination, blood test, urine test and stool test.

Examination

Your doctor will examine your child, and talk to you or your child about the symptoms and any medicines that your child takes.

Your child's **blood pressure** will be measured, using a special instrument. This is because HUS may cause high blood pressure, or **hypertension**.

Blood test

A small amount of blood will be taken from a **vein**, with a needle and syringe, for a **blood test**. The sample will be sent to a laboratory for testing. The blood test will look for:

- information about blood cells
- signs of a recent infection by *E. coli* or another germ
- how well your child's kidneys are working
- the amounts of important chemicals in your child's blood.

Urine test

You or a nurse may need to collect some of your child's urine in a small, clean container for a **urine test**. A **dipstick** will be dipped into the urine – this is a strip with

chemical pads that change colour depending on what substances are in the urine. The sample may also be sent to a laboratory for more accurate tests.

Children with HUS may have blood cells and/or protein in their urine.

Stool test

Your child will need a **stool test**, which is normally done at the hospital. A nurse will collect a stool (poo) sample from your child.

Children with HUS may be found to have STEC in their stool.

Telling the local health protection unit

If your doctor finds 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.

Tests and diagnosis: Read more about blood tests for HUS

Information about blood cells and haemoglobin

A **full blood count** measures the numbers of different types of blood cells. Children with HUS normally have a low number of **platelets**, blood cells that form clots to help the body heal. They may also have a low amount of **haemoglobin**, the substance on red blood cells that carries oxygen round the body.

In a **blood film**, a thin layer of blood is examined under a microscope. In HUS, this may show broken **red blood cells** (these are called fragments).

Infection

A blood test can check if there are any **antibodies**, proteins that are made by the immune system to find and kill specific germs. This gives information about whether there has been an infection caused by *E. coli*, or STEC.

How well the kidneys are working

Urea and **creatinine** are chemicals that are made in the body. They are waste products and normally removed by the kidneys into urine. In severe cases of HUS, these may build up and there are higher amounts of these in the blood than usual.

The blood test can also find out how well the kidneys are working (kidney function), by measuring the amount of creatinine in the blood. This can be used to estimate the **glomerular filtration rate (GFR)**, which is the amount of fluid (liquid) the kidneys filter each minute.

Other chemicals

Electrolytes are chemicals in the body – we need the right balance of these to stay healthy. Some important electrolytes include the following:

- **sodium** helps balance the amount of water in the body
- **potassium** is needed for the muscles, including the heart muscle, to work properly
- **bicarbonate** balances the amount of acid in our body, or the pH balance (also called the acid–base balance)
- **phosphate** is important for bones, teeth and muscles
- **calcium** is important for bones and teeth, helps blood to clot and also helps the muscles, including the heart muscle, to work.

Treatment

Children with STEC-HUS are usually admitted to hospital, where they are carefully monitored during their illness to make sure they have the right amounts of water, salts and nutrients. Some children need medicines to help treat complications of the disease, such as high blood pressure (hypertension), high blood sugar and anaemia. Some children need a blood transfusion. More rarely, surgery on the tummy is needed.

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

Further information is given below.

→ It is important that your child follows any treatment plan outlined by your doctor.

Where will my child be treated?

Hospital stay

Your child will probably be admitted to hospital for a few days or a few weeks. He or she will be looked after by a **paediatrician**, a doctor who treats babies, children and young people.

If your child is suspected of having a STEC infection, he or she needs to stay in an **isolation cubicle**. This is a special area of the hospital that keeps your child away from other patients. This is because STEC can be passed on to others very easily. Your hospital staff will let you know if there is anything you need to do to prevent spreading the infection.

Referral to specialist services

Many children are referred to a **paediatric renal unit**, a specialised unit for babies, children and young people with kidney conditions, which may be in a different hospital. This is often needed for children with some complications, including **hypertension** and/or **acute kidney injury** (when the kidneys stop working as well as they should), and who may need dialysis.

Monitoring in hospital

Your child's healthcare team will carefully monitor your child to make sure he or she has the right amounts of water, salts and minerals in his or her blood. Your child may need an intravenous infusion, or a drip, to get fluids into his or her body.

» [Read more on the next page](#)

Nutrition

Changes to eating and drinking

Your child will need good nutrition (food) during this illness, and this will be carefully monitored, especially if his or her kidneys are not working properly. It is important that your child has enough calories (energy) and the right amounts of **electrolytes**, which are minerals such as sodium (salt), potassium, phosphate and calcium. Your child may also need to drink less fluid, such as water, squash and soft drinks.

Your doctor, nurse or a **renal dietitian** will give you more information about your child's needs.

Treatment: Read more about your child's healthcare team

Your child's healthcare team may include a:

- **paediatric nephrologist** – a doctor who treats children with kidney problems
- **renal nurse** – a nurse who cares for children with kidney problems
- **paediatric dietitian** – a professional who advises what your child should eat and drink during different stages of a kidney condition
- **renal social worker** – a professional who supports you and your family, especially with any concerns about money, travel and housing related to looking after your child with kidney disease.
- **renal psychologist** – a healthcare professional who supports your child and family, especially with emotional stresses and strains from having or look after a child with kidney disease
- **play specialist** – a professional who uses dolls and other toys to help your child prepare for procedures, such as blood tests and dialysis
- **renal pharmacist** – some hospitals have a pharmacist who specialises in medicines for children and/or adults with kidney problems.

Your child's kidneys may stop making as much urine as normal, or sometimes make none at all. His or her healthcare team will check how much your child is drinking and how much urine he or she is passing, to make sure he or she does not have too much fluid or too little fluid (**dehydration**). They may also weigh your child.

An intravenous infusion, or drip, may be used to get fluids into the body. A doctor or nurse will insert a **cannula**, a plastic tube, into your child's vein. This is connected to a bottle or bag containing fluid, which drips through a tube into the vein.

Your child's healthcare team will also check your child's kidney function (how well his or her kidneys are working). They will test your child's urine with a dipstick and check his or her blood pressure.

Help with feeding

Some children with HUS may feel sick (nausea), be sick (vomit) or have tummy pain, and they may not want to eat very much or anything at all. Your healthcare team can place a tube or an intravenous line to give feeds with calories and electrolytes, as well as water and medicines if needed.

- **Enteral feeding** gives feeds directly into the stomach. A **nasogastric tube** is a long, thin tube that is placed through the nostril, down the throat and into the stomach. It is inserted using special medicines so your child cannot feel pain or is asleep. If your child needs dialysis, the tube may also be placed at the same time as preparing for this treatment.
- **Parenteral feeding** gives feeds directly into the bloodstream. A 'line' is inserted into one of the large veins in your child's neck – this is usually done under **general anaesthetic** so your child can sleep through the procedure.

Controlling blood pressure

Children with STEC-HUS may have high blood pressure, or **hypertension**. Their blood pressure will need to be controlled so it is in a healthy range.

If your child has hypertension, he or she may need to change what they eat and drink, and may need to take medicines.

» [Read more in the infoKID topic Hypertension](#)

Controlling blood sugar

A small number of children get **pancreatitis**, when the pancreas, which makes and releases chemicals that break down food, becomes inflamed. This can lead to **diabetes**, when there is too much sugar in the blood.

Some children need to take **insulin**, a **hormone** that is normally made by the pancreas, to help control the amount of sugar in their blood. This is given with a needle. This problem usually gets better over time.

» [Medicines for Children: Insulin for diabetes](#)

Treating anaemia

Children with STEC-HUS get **anaemia**. The blood has fewer **red blood cells** or less **haemoglobin**, a substance that is in red blood cells. Because red blood cells and haemoglobin carry oxygen around the body, children with anaemia often feel weak and tired, and may look paler than usual.

Medicines

In some children, anaemia can be treated with folate (folic acid) medicines that help the body make more haemoglobin. These are usually taken by mouth.

» [Medicines for Children: Folic acid for haemolytic anaemia](#)

Blood transfusion

Many children have more severe anaemia, and need a **blood transfusion** to receive healthy blood from a **blood donor** (another person who has given some of their own blood). A transfusion usually takes a few hours, and blood is given through a plastic tube in a vein. Children who have had a blood transfusion do not need to take folate medicines.

Dialysis for kidney problems

The kidneys do not work as well as normal during this illness – we say there is **reduced kidney function**. Most children develop **acute kidney injury (AKI)**, where the kidneys quickly stop working properly. In some children, the kidneys get better over time.

However, about half of children with STEC-HUS need **dialysis** while their kidneys are not working properly. Dialysis uses special equipment or a machine to 'clean' the blood, removing waste products and extra water and salts, and sometimes adding important salts. Most of these children need this treatment for a short time only, but a few need it for longer.

Types of dialysis

There are two types of dialysis. Your child's healthcare team will give you information so you understand the benefits and risks of each type, and the surgery that is needed to prepare for dialysis.

- **Haemodialysis:** your child is connected to a machine, usually for a few hours at a time, which cleans his or her blood. Your child will have a catheter (a long thin tube), or a 'line', inserted into one of the large blood veins in his or her neck – special medicines are used so your child does not feel any pain. Blood is pumped out of the body through a tube, into the machine, where it passes through an 'artificial kidney' called a **dialyser**, which is like a filter. The cleaned blood is then returned to the body through another tube. Blood is pumped out of and into the body quickly – only a small amount of blood is outside the body at any time.
- **Peritoneal dialysis:** your child's peritoneum, which is the lining of the abdomen (tummy), is used to clean his or her blood. Your child will have a catheter inserted into his or her **peritoneal cavity**, which is a space around the organs in the abdomen. A special fluid (called **dialysate**) is put into the abdomen, where it sits for a few hours or longer, while the peritoneum filters the blood. The waste products, extra water and salts in the blood move into the fluid, and then this is drained out of the body. This can take place overnight, or several times a day.

» Dialysis – an introduction

Plasma exchange for cerebral HUS

Rarely, STEC-HUS affects the central nervous system, including the spine and brain – this is called **cerebral HUS**.

Plasma exchange (also called **plasmapheresis**) is sometimes recommended for these children. However, doctors do not yet have enough evidence to know whether this procedure can help children with cerebral HUS. The aim is to remove substances that may be harming the body. Using a special machine, some blood is removed from the body and separated into two parts – blood cells and liquid (plasma). The blood cells are returned to the body, along with the liquid part of blood that may come from a donor or may be made in a laboratory.

Questions to ask the doctor or nurse

- What treatment does my child need?
- How will the treatment help my child?
- How can I help my child prepare for procedures and treatments?
- If the first treatment does not work in my child, what happens next?
- How will I know if we need to go back to the hospital or see the doctor?

Treatment: Read more about plasma exchange

Plasma is the liquid or watery part of blood. It helps carry **blood cells**, **protein** and other substances around the body.

Plasma exchange is a procedure that removes blood from the body, separates the plasma and any harmful substances, and returns the blood, with a plasma substitute, to the body.

- Each plasma exchange takes about 2–3 hours and is done in hospital. Some children will need more than one exchange.
- A **catheter**, which is a large tube, is inserted into one of the large **veins** in the chest or neck. This is usually the same catheter that is used for **haemodialysis**. Your child's blood is taken from his or her body through the catheter.
- Using special equipment, your child's blood is separated into two parts: the plasma and any harmful substances; and the blood cells.
- Your child's blood cells are added to a plasma substitute – either plasma or a protein called albumin from a donor, another person who has donated blood.
- This is then returned to your child's body through the catheter.
- As blood is taken from your child and returned to him or her at the same rate, only a small amount of blood is outside his or her body at any time.

Your child's doctor or nurse will give you more information about plasma exchange and how you and your child can prepare for it.

How children may be infected with STEC

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

People can become infected by:

- eating food that is contaminated with faeces of infected animals
- 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.

How to help prevent infection

Hand hygiene

- Teach good hygiene – wash hands before eating, after handling raw meat, after using the toilet or changing nappies, and after contact with animals.
- Supervise children closely to ensure that they wash their hands thoroughly.
- Do not use gels or wipes instead of washing hands with soap and water. Gels and wipes do not remove E. coli O157.

Cooking

- Cook meat products right through, especially minced meat.
- Use separate chopping boards and kitchen utensils for raw meat and cooked or ready-to-eat foods, to avoid contamination; store raw meat at the bottom of the fridge, to avoid juices dripping onto ready-to-eat foods.
- Only leave cooked foods, meat and dairy products out at room temperature for a short time. Avoid unpasteurised milk and cheese while your child is growing up.
- Thoroughly wash all salad vegetables and do not prepare them with utensils that have also been used for raw meat.
- If you have been ill with STEC, do not prepare food for others for at least 48 hours.

Visiting community farms or camping around farm animals

If your child has been in contact with animals, hand washing is especially important.

- Do not swim in water that you think may be contaminated by cattle and sheep in nearby fields.
- Camping or holiday homes, especially in very rural areas, may have water supplies that are not from the mains (and so can be contaminated by cattle or sheep in nearby fields).
- Avoid touching faces or putting fingers in mouths while in farm environments.
- Do not kiss farm animals or allow children to put their faces close to animals.
- Wash hands thoroughly with soap and water after touching animals, fences or other surfaces in animal areas.
- Do not eat or drink while touching animals or walking round a farm and only eat and drink in picnic areas or cafes.
- Wash hands thoroughly with soap and water before eating or drinking.
- Remove and clean boots or shoes that might have become soiled, and clean pushchair wheels. Then wash hands thoroughly with soap and water.

What to do if you think your child has an infection

→ If your child develops a tummy bug and you think it may have been caused by something he or she ate, you should take your child to your family doctor (GP) to have this confirmed. Certain illnesses, particularly those caused by food, have to be reported officially in case there is an outbreak.

Your doctor will need to report this to the local health protection unit. This will help make sure other people – especially young children and the elderly – do not catch the infection.

About the future

Most children fully recover from STEC-HUS, and do not have long-term problems. It is usually a single episode, and so does not come back again. Children who need dialysis for more than two weeks are more likely to have long-term kidney problems.

Risk of death

There is a small risk of death with this disease. Reports indicate that less than 2 children in 100 with STEC-HUS die. This usually happens shortly after they first develop the disease.

In a recent UK study 7 out of 389 children with diarrhoea-associated HUS died during the acute illness (when the child first became sick with HUS). They were more likely to die when other parts of their body, such as the brain, were severely affected. The study showed that the survival rates had improved since an earlier study.

Follow-up

Your child will need to have follow-up appointments at the hospital. If your child needed dialysis, he or she may need to continue going to these throughout their life. It is important to go to these appointments, even if your child seems well. You will also have the opportunity to ask any questions.

At these appointments, your child may have his or her height and weight checked, and a physical examination.

Blood pressure

Your child will need to have **blood pressure** measurements – at first, very often, and later about once a year. About a quarter or a third of patients who have had STEC-HUS have high blood pressure (**hypertension**) and this will need to be controlled.

Blood tests

Your child may need **blood tests** to check for the amount of protein and other substances in his or her blood, and measure his or her kidney function.

Urine test for protein

Your doctor will do **urine tests** to check whether there is more protein in your child's urine than usual (**proteinuria**).

If there is proteinuria, this may be a sign that your child's kidneys are not working as well as they should. Your child may need to take a medicine to try to reduce the amount of protein in his or her urine – the medicine may be an **angiotensin-converting enzyme inhibitor (ACE inhibitor)** or **angiotensin-II receptor blocker (ARB)**.

Impact on your child and family

Children who make a full recovery from HUS can usually do all the things that other children their age do. They should be able to go back to school or nursery, play with other children and stay active.

Living healthily

Your child can help protect his or her kidneys by leading a healthy lifestyle through their child and adult years. This includes:

- eating a healthy diet – with at least five servings of fruit and vegetables a day, taking care not to eat too much salt, sugar and fats (especially saturated fats)
- getting plenty of exercise
- not smoking.

Long-term problems

Chronic kidney disease

A few children will have long-term problems with their kidneys. Their kidneys stop working as well as they should – this happens slowly, often over many years. This is called **chronic kidney disease (CKD)**. These children will need further, specialist treatment in the future. If your child has CKD, you and your family will learn more over time about how to help manage the condition, and what to expect.

Other long-term problems

Some children have complications in other parts of their body. Many recover from these, but they may need follow-up – a few children will have long-term problems, including:

- **diabetes** (higher amount of sugar in their blood) – they will need to take insulin as a medicine
- **colitis** (when the colon, or bowel, gets inflamed)
- **cerebral HUS** (affecting the central nervous system, including brain) – including seizures (convulsions or fits), problems with vision, or paralysis (when part of the body cannot move).

Further support

This can be a difficult and stressful experience for your child and the whole family, including other children. If you have any concerns or need additional support, speak with your doctor or nurse.

Resource

HUSH (Haemolytic Uraemic Syndrome Help)

UK PO Box 159 Hayes UB4 8XE; Tel: 0800 731 4679;
Web: www.ecoli-uk.com

Further information

This is the end of the information on STEC-HUS. If you would like to read more about other kidney conditions and other supporting information, you can find a list of topics covered on the infoKID website at www.infoKID.org.uk.

Your notes and contact information

www.infoKID.org.uk



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For details on any sources of information used in this topic, please contact us through our website www.infoKID.org.uk. We take great care to make sure that the information in this leaflet is correct and up-to-date. However, it is important that you ask the advice of your child's doctor or nurse if you are not sure about something. This information is intended for use in the United Kingdom, and may not apply to other countries.

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