

Henoch-Schönlein purpura (HSP) with kidney involvement

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

Henoch-Schönlein purpura (HSP) is a condition that affects different parts of the body. Tiny blood vessels in the body become inflamed or swollen. HSP happens in people of all ages, but is most often seen in children under 10 years of age. It is not contagious, so cannot be passed on to other people.

Children with HSP get red or purple raised spots on their skin. They may have pain in their joints and/or tummy, and they may feel sick and tired. Sometimes HSP also affects their kidneys, causing blood cells and proteins to 'leak' into the urine.

Usually, children with HSP do not need special treatment, but will need to be carefully monitored and may need to stay in hospital and/or take medicines.

Most children start to feel better after several days or a few weeks, and the rash and other symptoms disappear. HSP occasionally comes back, usually within a few months, and may need further treatment. A few children have long-term problems, especially when their kidneys are affected. They will need to be monitored and may need specialist treatment.



Overview

Symptoms and complications

Symptoms and signs

Common symptoms and signs of HSP include:

- **purpura** on the skin – a rash of red or purple spots that are raised and can be felt, especially on the feet, ankles, backs of legs, buttocks, lower back and arms; some children also have bruising
- pain and swelling in the joints – especially the ankles, knees and elbows
- pain in the abdomen (tummy) – children may feel sick (nausea), be sick (vomit) or have constipation or diarrhoea; sometimes there is blood or mucus in the stools (poo) or vomit
- feeling tired.



An example of purpura (rash)

- blood in the urine (**haematuria**) – you cannot always see the blood, but if there is a lot, the urine may be coloured red or dark brown (like a cola drink)
- Protein in the urine (**proteinuria**) – you cannot usually see the protein, though it can be found on a simple **urine test**
- sometimes, urinating less often or passing smaller amounts.

Complications

Some children have **complications** – health problems that happen because of the condition.

When the kidneys are involved, this may lead to:

- blood pressure that is too high (**hypertension**)
- swelling or puffiness in different parts of the body, especially around the eyes, legs and feet (**oedema**).

Very rarely, the kidney problems get worse quickly (**rapidly progressive glomerulonephritis**), and this may cause the kidneys to stop working over a short time (**acute kidney injury**).

When the kidneys are affected, there may be other symptoms and signs:

Other complications include:

- in some boys, inflammation of the testicle (**orchitis**) – this may cause pain and/or swelling in the scrotum
- a blockage in the bowel (**intussusception**) – this needs surgical treatment
- very occasionally, the brain, spinal cord or lungs are affected.

» [More information about symptoms and complications](#)

Causes

HSP is linked to the **immune system**, which normally protects the body from infections and disease. Many children with HSP first get symptoms with or after an infection – usually in the throat or tonsils.

HSP is a **systemic condition** – this means it affects different parts of the body. The blood vessels swell and leak fluid into the tissues around the blood vessels, causing the symptoms.

When the kidneys are involved

Most of us have two **kidneys**. They are part of the urinary system, which gets rid of things that the body no longer needs, so that we can grow and stay healthy. The kidneys filter blood and remove extra water, salt and waste in urine (**wee**).

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

In about half of children with HSP, the kidneys are affected. The tiny blood vessels in the kidneys, which filter blood to remove extra water, salt and waste into the urine, become inflamed. This causes the kidneys to 'leak' blood cells and proteins into urine. This is sometimes called HSP nephritis.

» [More about causes](#)

Test and diagnosis

Your child will need some tests to diagnose HSP and find out whether he or she needs any treatment. Your child's doctor will examine your child, discuss his or her symptoms, and check his or her blood pressure. Your child will need one or more **urine tests**. He or she may need other tests, such as **blood tests** and an **ultrasound scan**.

A few children need a **biopsy** of the skin and/or kidneys – a tiny piece of tissue from the skin or kidney is removed from the body with a needle and examined under microscopes. Special medicines are used so your child does not feel any pain or can sleep through the procedure.

» [More about tests and diagnosis](#)

Treatment

Where will my child be treated?

Your child will probably be treated in a **paediatric unit**, a special part of your hospital for children. He or she will be looked after by a **paediatrician**, a doctor who treats babies, children and young people.

Your child may need to stay in hospital for a few days or longer. However, children with HSP usually have most of their care as **outpatients**, visiting the hospital during the day.

A few children with HSP are referred to a **paediatric renal unit**, a specialised unit that treats babies, children and young people with kidney problems and may be in a different hospital to your own. Your child will be looked after by a team, including a **paediatric nephrologist**, a doctor who treats children with kidney problems.

About treatment

Most children do not need special treatment. To relieve pain, your child may take medicines such as paracetamol (e.g. Calpol®).

→ **Do not give your child ibuprofen (e.g. Brufen) as it can cause further damage to his or her kidneys.**

Some children need to make temporary changes to what they eat or drink, or take medicines to try to reduce the amount of protein lost in their urine, control their blood pressure or treat any complications.

» [More about treatment](#)

About the future

Will my child get better?

In most children, the symptoms and signs of HSP go away within one month, though some children will have problems for three months or even longer. The purpura (rash) on the skin disappears – and usually does not leave any scars – and the joint pain and tummy pain go away. This is called remission.

In a few children, the symptoms and signs come back, usually within one year. This is called a **relapse**. These children may need further treatment.

Follow-up

Your child will probably need to be seen regularly by a doctor for some weeks, to check for any problems with his or her kidneys. After your child recovers, he or she may need follow-up appointments once a year for urine tests and blood pressure measurements.

If your child has **acute kidney injury** (when the kidneys stop working properly), he or she will need follow-up throughout their life.

Long-term effects

Most children have no long-term effects from HSP.

Some children continue to have **haematuria** (blood in their urine) – this usually cannot be seen but is picked up on a urine test. Up to 15 children in 100 continue to have proteinuria (protein in the urine) one year after the initial episode of HSP – they will need to be monitored.

A small number of children (less than 5 in 100) with HSP have long-term problems with their kidneys – this is called

chronic kidney disease (CKD). Their kidneys stop working as well as they should – this happens slowly over many years. If your child has CKD, you will learn more over time about how to help manage the condition, and what to expect.

» **More information about the future**

Symptoms and complications

HSP can affect different parts of the body and The symptoms vary among different children.

Skin

All children with HSP have **purpura**, red or purple spots, over their skin, which look like a rash. These spots are usually raised so you can feel them (we say they are **palpable**). They are usually in groups and symmetrical (they look the same on both sides). The purpura usually appear on the feet and ankles, legs, buttocks, lower back and arms. Children under 2 years may also have purpura on their head, chest and back. Your child may get more purpura as time goes on.

The purpura happens when the small blood vessels under the skin get inflamed and leak blood into the surrounding tissues. It is not contagious, and other people cannot catch purpura by touching your child's skin.

Your doctor or nurse will give you more information about anything you need to do to. You may wish to speak with staff at your child's nursery or school about the rash. They may be able to reassure other families that the rash cannot be passed on.

In most children with HSP, the purpura goes away after several weeks, though some will have a rash for a few months or longer. It is rare for the purpura to leave any scars.

Joints

Many children with HSP have pain and/or swelling in their joints. This usually happens in their knees and elbows, and sometimes their ankles and wrists.

In some children, the pain may be severe, and may cause difficulty walking or moving around.

Abdomen

Many children with HSP have **abdominal pain** (pain in the tummy). This happens when small blood vessels in the lining of the stomach and the intestines (gut) leak blood. Your child may:

- feel sick (nausea) or be sick (vomit)
- have constipation or diarrhoea
- sometimes, have blood or mucus in his or her stools (poo) or vomit.



An example of purpura (rash)

Other symptoms

- Your child may feel more tired than usual.
- Some boys have **orchitis**, when the testicle becomes inflamed – this can cause the scrotum to swell up, and become tender and red. If you think this may be happening to your child, take him to your doctor.

Blockage in the bowel

In a few children with HSP, one part of the bowel (intestine) slides into the next part – this is called **intussusception**. This is like the parts of a telescope collapsing into each other. The walls of the intestine can press against each other and create a blockage, which can lead to swelling and less blood flowing into the affected areas. It usually happens suddenly.

Children may:

- have severe pain (like colic) every 10–20 minutes – babies or young children may cry and draw up their legs to the chest
- vomit
- feel tired or not be able to concentrate
- pass stools with blood in them – they may look like redcurrant jam or jelly.

Your doctor can diagnose intussusception by doing a physical examination and doing tests, including **blood tests** and **imaging tests** (scans). Children with intussusception will need treatment at a hospital. This may be a type of **enema** (pushing air or liquid into the back passage to cure the blockage) or surgery. Your doctor will give you more information.

Other complications

Very rarely, the brain or lungs are affected. Children with HSP affecting the brain can appear confused or unresponsive or can have fits (seizures). If the lungs are affected then this can cause bleeding in the lungs. These are very rare and will need treatment in a hospital. If this is the case, your doctor will give you more information.

What can happen when HSP affects the kidney?

In about half of children with HSP, the kidneys are affected, leading to the following. These may not happen for some days or weeks after the above symptoms.

- **Haematuria** (blood in the urine). This happens when red blood cells leak through the kidney's filters into the urine. Sometimes you cannot see the blood, but if there is a lot, the urine may be coloured red or dark brown (like a cola drink).
- **Proteinuria** (more protein in the urine than normal). This happens when proteins leak through the kidneys' filters into the urine. You cannot usually see the protein, but it is picked up on a urine test.
- Some children urinate less often or pass smaller amounts.

This is referred to as **HSP nephritis** (HSP with kidney involvement). This may cause some of the following problems.

High blood pressure

Hypertension, blood pressure that is too high, can occur in HSP nephritis. There are often no symptoms, though some children develop headaches, vomiting or blurred (fuzzy) vision. Hypertension that lasts a long time can also increase the risk of getting other diseases in adulthood.

These children will need to control their blood pressure so it is in the healthy range. They may need to reduce the amount of salt they eat or make other changes to their diet. Some children take medicines to help control their blood pressure.

Swelling in the body

Some children with HSP nephritis get swelling or puffiness in different parts of the body, especially around their eyes, legs and feet – this is called **oedema**.

Rapidly progressive glomerulonephritis

Very rarely, the kidney problems get worse quickly – this is called **rapidly progressive glomerulonephritis** or **crescentic glomerulonephritis**.

This may lead to **acute kidney injury (AKI)** – when the kidneys stop working over a short time. Some children get better after a few weeks, and some need to take medicines or have more intensive treatment.

Symptoms and complications: Read more about swelling in the body

In HSP, the kidneys sometimes leak a large amount of one type of protein – especially a type called **albumin** – into the urine, and so there is not enough in the body. Albumin helps fluid (water) move in and out of the bloodstream, so that the body's cells can be nourished, or fed. When there is not enough albumin in the blood, the fluid cannot move back into the bloodstream. The fluid stays in parts of the body, and this causes the swelling. When this happens it is called **nephrotic syndrome**.

Causes

HSP is a systemic condition – this means it affects different parts of the body. It is a type of vasculitis – the blood vessels are inflamed (swollen) and leak fluid into the tissues around the blood vessels.

HSP gets its name from two German doctors who described the condition – Edouard Henoch and Johan Schönlein.

After infection

Many children with HSP first get symptoms with an infection, caused by bacteria or viruses (germs). This infection is not in the kidney, but usually in the throat or tonsils. Most children recover from these infections. But, in a few children the infection seems to trigger HSP.

The immune system

HSP seems to be linked to the **immune system**, which normally protects the body from infections and disease.

A protein called immunoglobulin A (IgA), which is made by the immune system, gets trapped in small blood vessels, causing the swelling.

How the kidneys are involved

When the kidneys are involved

In about half of children with HSP, the kidneys are affected. This is sometimes called **HSP nephritis** ('nephritis' means kidney disease).

The kidneys have many filters that clean blood to remove water, salt and waste into urine. These are made up of tiny blood vessels called **glomeruli**.

In HSP, immunoglobulin A (IgA) is deposited (placed) on the filters, causing them to swell. They leak proteins and blood cells into urine.

» About the urinary system and kidneys

IgA nephropathy

Doctors think that HSP with kidney involvement is related to the kidney condition, **IgA nephropathy** – the same proteins (immunoglobulin A) are trapped in the glomeruli. However, in IgA nephropathy only the kidneys are involved, and children do not have a skin rash, joint pain or abdominal pain.

Will it affect other family members?

HSP does not usually run in families. If one of your children has this condition, it is unlikely that another of your children or another family member will get it.

It is not contagious, and cannot be passed on to other people.

Causes: Read more about the immune system

Germs

The immune system protects the body against germs such as bacteria and viruses that can cause illness. These germs can enter the body in lots of ways, such as by the nose and throat or the urinary system. If we get a cold or flu, this means that a virus germ has got into the body and started to infect some of our body's cells.

Germs have special 'markers' that are different from the markers on our own body's cells. This means that the immune system can recognise that they are germs and kill them. We often feel sick for a few days or a few weeks while this is happening.

Parts of the immune system

The immune system has many different ways to protect the body against disease. Some of the parts include those listed below.

- **White blood cells** are living cells in the blood. Often, the number of white blood cells found in a **blood test** can give information about someone's immune system. The two main types of white blood cells in the immune system are neutrophils and lymphocytes.
- **Antibodies** or **immunoglobulins** recognise the germs that have come into the body, and can bind (stick) to them. There are five types: immunoglobulin A (IgA), immunoglobulin D (IgD), immunoglobulin E (IgE), immunoglobulin G (IgG) and immunoglobulin M (IgM).
- The **complement system** is made up of other proteins that float in the blood. These proteins work with (complement) other parts of the immune system to help kill germs or cells infected by germs. Normally, the body controls when complement is activated, so it does not attack the body itself.

When the immune system does not work properly

Sometimes the immune system does not work as expected and can cause problems. For example, sometimes the immune system cannot recognise the body's own cells and may attack them as if they were invaders like germs.

How the kidney works

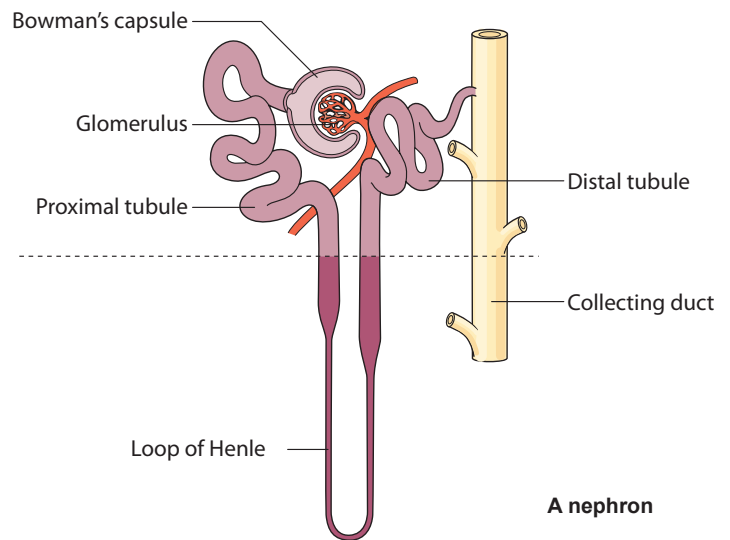
Inside each kidney, there are about one million **nephrons**. Each nephron is made up of a **glomerulus** (when we talk about more than one glomerulus, we say glomeruli), and a **renal tubule**.

- 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 HSP

A protein called immunoglobulin A (IgA) gets trapped in the glomeruli. This causes the glomeruli to become inflamed (swollen) or damaged. The damaged glomeruli can let blood cells and protein through, which means they go into the urine.



Tests and diagnosis

Your child will need some tests to diagnose (identify) HSP and find out whether he or she needs any treatment. Your doctor will do an examination, measure your child's blood pressure, and do one or more urine tests. Your child may need other tests, such as blood tests, an ultrasound scan or a biopsy of his or her kidney or skin.

Examination

Your doctor will talk to you or your child about their symptoms and any medicines that he or she takes. The doctor will examine your child – for example, to look at the **purpura** (rash).

Your doctor or nurse will check your child's **blood pressure**. This is because HSP may lead to high blood pressure (**hypertension**).

Urine tests

You or a nurse will 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. This shows whether there are blood cells and/or protein, which are signs of HSP with kidney involvement. The sample may also be sent to a laboratory for more accurate tests.

Blood tests

Your child may need one or more **blood tests**. A small amount of blood will be taken from a vein, with a needle and syringe for a blood test. A special gel or cream can be used to help your child stop feeling any pain. The blood test results can give the doctor more information, including:

- how well your child's kidneys are working – this is called the **kidney function**
- about the immune system, and whether there has been a recent infection
- the level of protein in your child's blood
- the numbers of types of blood cells and information about how the blood forms **blood clots** (when blood clumps together to control bleeding)
- the amount of other substances, including important chemicals called **electrolytes**.

» **Read more about blood tests for HSP on the next page**

Imaging tests

Some children need **imaging tests** (scans). These use special equipment to get images (pictures) of the inside of their body.

- **Ultrasound scan** – looks at the shape and size of kidneys and other parts of the urinary system. A small handheld device is moved around your child's skin and uses sound waves to create an image on a screen. Boys who have swelling in their scrotum may also need an ultrasound scan of this part of their body.
- **Chest x-ray** – for children with breathing problems, chest x-ray checks for any fluid (liquid) around the lungs. Your child sits or lies still for a few seconds while a machine takes x-ray pictures.

Occasionally, other imaging tests are needed.

Skin and kidney biopsy

In a **biopsy**, a tiny piece of a body tissue is taken from the body and examined under microscopes. Special medicines are used so your child does not feel any pain or can sleep through the procedure.

Skin biopsy

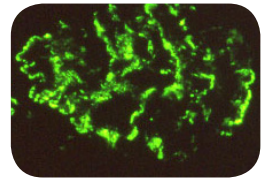
A **skin biopsy** can confirm whether the purpura is caused by HSP. This is rarely needed and your doctor will give you more information about this procedure.

Kidney biopsy

A **kidney biopsy** can find out more about the kidneys' health. This is rarely needed, and usually for children with:

- swelling in their body (**oedema**) when the kidneys leak a lot of protein
- significant amounts of protein in their urine (**proteinuria**) for more than four weeks
- **acute kidney injury** – when the kidneys stop working properly over a short time.

It can take a few weeks to get the results from a biopsy.



Kidney showing IgA immunofluorescence

Tests and diagnosis: Read more about blood tests for HSP

How well the kidneys are working

Urea and **creatinine** are chemicals that are made in the body. They are normally removed by the kidneys into urine. In severe cases of HSP, these may build up in the blood.

The kidney function can be checked by measuring the **glomerular filtration rate (GFR)**. The GFR is the amount of fluid the kidneys filter each minute. It can be estimated by measuring the amount of creatinine in the blood.

Infection and immune system

A blood test can check levels of **immunoglobulins** or **antibodies** – the body's immune system makes these unique proteins to identify and kill specific germs. This gives information about whether there has been an infection, and sometimes which germ caused it.

Some children with HSP have high levels of immunoglobulin A (IgA), an antibody, in their blood. When the kidney is involved, IgA can be trapped in the **glomeruli**, the kidney filters.

Protein in the blood

Some children with HSP lose a lot of protein in their urine, when it is leaked through the glomeruli. This means there is less protein in their blood, especially a type of protein called **albumin**. Because albumin is smaller than other proteins, it is more likely to leak through the glomeruli.

Electrolytes

Electrolytes are important 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.

Full blood count and blood clotting test

A **full blood count (FBC)** counts the numbers of different types of blood cells – a higher or lower level of these may be a sign of infections or other health problems.

A **blood clotting test** look at how the blood forms clots, when the blood clumps together – for example, when we have a cut, to stop the body losing too much blood.

Treatment

Most children with HSP do not need special treatment. They are carefully monitored by a team of healthcare professionals at the hospital. Most children recover from HSP after a few weeks or a few months – the purpura (rash), joint pains and stomach pains disappear.

Some children need treatment – for pain, complications or kidney problems – which are explained below.

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

Where will my child be treated?

Your child will probably be treated in a **paediatric unit**, a special part of your hospital for children. He or she will be looked after by a **paediatrician**, a doctor who treats babies, children and young people.

Your child may need to stay in hospital for a few days or longer. However, children with HSP usually have most of their care as an **outpatient**, visiting the hospital during the day.

Referral to specialist care

A few children are referred to a **paediatric renal unit**, a specialised unit that treats babies, children and young people with kidney problems and may be in a different hospital to your own. They are looked after by a **paediatric nephrologist**, a doctor who treats children with kidney problems.

Managing pain and nausea

To help manage any joint or tummy pain, your child may take medicines such as paracetamol (e.g. Calpol®).

You can get paracetamol or other medicines for pain from your pharmacist, in a form that is best for your child. Make sure you follow the instructions given with the medicine. Wait at least 4 hours between doses of paracetamol, and do not give more than four doses in 24 hours.

» **About paracetamol for mild-to-moderate pain (Medicines for Children)**

Speak with your doctor or nurse if you need more support.

→ **Do not give your child ibuprofen (e.g. Brufen) – this medicine may cause further damage to kidneys that are affected by HSP.**

Treatment: Read more about hospital visits and the healthcare team

Hospital visits

A team of healthcare professionals will:

- check your child's **kidney function** (how well his or her kidneys are working)
- measure how much your child is drinking and how much urine he or she is passing
- test your child's **urine** with a dipstick
- check your child's **blood pressure**.

Healthcare team

Your child's healthcare team may include a:

- **paediatrician** – a doctor who treats babies, children and young people
- **paediatric nephrologist** – a doctor who treats children with kidney problems
- **radiologist** – a healthcare professional who uses **imaging tests** (scans) to help identify a condition
- **renal nurse** – a nurse who cares for children with kidney problems
- **renal dietitian** – a healthcare 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 to 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

Reducing protein loss in urine and controlling blood pressure

Some children need to take medicines for:

- **proteinuria** – to reduce the amount of protein lost in their urine, and/or
- **hypertension** – to reduce or control blood their pressure so it is in the healthy range.

These are usually medicines called **angiotensin-converting enzyme inhibitors (ACE inhibitors)** or **angiotensin-II receptor blockers (ARBs)**. Common ACE inhibitors are: captopril, enalapril and lisinopril.

Doctors understand that, in some children, these medicines will reduce the risk of long-term kidney problems.

→ It is important that you follow your doctor's instructions about when and how much to give. Do not stop the medicine suddenly.

Steroid medicines

Your paediatrician may prescribe steroid medicines to your child – this is usually the medicine **prednisolone**. This is usually for children with:

- severe stomach pain
- swelling in their body (**oedema**) when the kidneys leak a lot of protein
- significant **proteinuria** for more than four weeks
- **acute kidney injury** – when the kidneys stop working properly over a short time.

Steroids are chemicals that are made naturally in the body but can also be made as medicines. They suppress the immune system – stop it from working to avoid harming the body.

How to give medicines

Your doctor will let you know how often and for how long to give the steroids. He or she will work out the amount of medicine (dose) that is right for your child – this will be shown on the medicine label.

→ It is important that you follow your doctor's instructions about when and how much to give. Do not stop the medicine suddenly.

Vaccines

It is important that your child has the **vaccines** (immunisations) that he or she needs to reduce the risk of some diseases. Speak with your doctor about these – some vaccines (live vaccines) are not safe to give while a child is taking steroids.

Infections

Children taking these medicines are more likely to get infections. Speak with your doctor or nurse, and your child's teacher or daycare manager, about how you can help prevent infection. Contact your doctor straight away if your child:

- has been in contact with someone who has chicken pox (if they have not had this illness before) or measles (if they have not had the MMR vaccine, which protects against measles, mumps and rubella); or
- is unwell and you are worried about an infection.

If your child does get an infection, he or she may need to take an **antibiotic** medicine, which kills the germs that cause infection. Your child must take the medicine for the number of days that the doctor has told you, or until all of the medicine has been taken.

» **More about antibiotics (Medicines for Children)**

Side-effects you need to do something about

We use medicines to help children get better, but sometimes they have effects we do not want – **side-effects**.

Contact your doctor straight away if your child has any of the following while on steroid medicines:

- fever (temperature above 38°C), with a sore throat or a cough, for more than 12 hours
- a rash or severe bruising
- bad stomach pain or repeated vomiting – sometimes steroids can cause ulcers in the stomach.

Treatment: Read more about a no-added salt diet

Eating too much salt can worsen **oedema** (swelling in the body) and can increase the risk of developing **hypertension** (high blood pressure), especially while on steroid medicines.

Your child should avoid eating or drinking lots of salted nuts, crisps, crackers, soft drinks, fast food meals, takeaways and processed foods (meals that are pre-prepared, including soups) – these often have more salt than we think. Do not add extra salt to meals that you cook or at the dining table.

Your doctor, nurse or a **paediatric dietitian** at the hospital will be able to give you more information.

Other side-effects

Other side-effects that affect some children are below – speak with your doctor or nurse if you are concerned or need more support:

- nausea, vomiting, stomach pain and/or indigestion (heartburn) due to irritation to the lining of the stomach – your doctor may give your child some medicine to treat this
- behavioural problems – you may find that your child is more likely to have tantrums, be moody, feel depressed, have difficulty sleeping or have nightmares
- weight gain and larger appetite – you can help by making sure your child has lots of physical activity and eats fruits, vegetables and low-calorie food, rather than food that is high in calories (such as cakes, biscuits, sweets and crisps), and by reducing the portion size
- high blood pressure (**hypertension**) – your child's blood pressure will be regularly checked, and if it is too high, will need to be controlled by eating a diet with no-added salt.

There may, sometimes, be other side-effects that are not listed above. If you notice anything unusual and are concerned, contact your doctor.

When steroids are needed over a long time, or in high doses, they may have other side-effects.

Changes to eating and drinking

Children who have oedema, are taking steroids or have acute kidney injury may need to make temporary changes to what they eat and drink. For example, they may need to eat a no-added salt diet and less of certain foods, and/or drink less fluid, such as water, squash and soft drinks.

Managing reduced kidney function

Some children with HSP develop reduced kidney function, which means that their kidneys do not work as well as normal. The severity of this varies, but most do not need any special treatment and their kidney function will return to normal.

A very small number will have more serious kidney problems and will need **dialysis**. This uses special equipment or a machine to do what a healthy kidney does – remove waste products and excess water from the body. Most of these children need this treatment for a short time only, but a few need it for longer.

Questions to ask the doctor or nurse

- What treatment does my child need?
- How will the treatment help my child?
- How long will my child be in hospital?
- 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?
- Will the HSP come back? How will I know?

Steroids: Read more about side-effects of long-term use of steroids

When steroids are needed over a long time, or in high doses, they may have other side-effects. If you have any concerns, talk to your doctor.

- All steroid medicines, including prednisolone, may affect the adrenal glands so that they produce less of a hormone called cortisol when the body is stressed (e.g. during illness or injury). This means that your child may have more difficulty fighting off an infection, or may recover less quickly from injury or after surgery. **If your child is unwell and you are worried about an infection, contact your doctor straight away.**
- Steroids can slow growth and affect puberty. They can also cause growth of body hair and irregular periods in girls. Your doctor will check your child's growth and development.
- Your child's skin may become thinner, and heal more slowly than usual. Acne (spots) may become worse, or your child may develop mouth ulcers or thrush (candidiasis).
- Your child may develop problems with their hip bones, or their bones may become weaker (osteoporosis). The muscles around their hips and shoulders may also become weaker. If your child has any difficulty walking or moving around, contact your doctor.
- Occasionally, steroids cause diabetes. If your child seems more thirsty than normal, needs to pass urine (wee) often, or starts wetting the bed at night, contact your doctor.

About the future

Your healthcare team will speak with you and your family about any long-term effects your child might have with HSP.

Urine testing at home

Your doctor may ask you to do urine tests at home to find out whether the HSP nephritis (HSP with kidney involvement) has gone away (gone into **remission**). You will be given special, clean containers to collect the urine and **dipsticks** to dip into the urine and check for any proteins and/or blood in the urine.

Your child's healthcare team will show you how to do this.

» **More about urine testing at home in Urine tests**

Remission and relapse

Remission

When the HSP goes away, this is called **remission**. In most children the symptoms and signs of HSP go away within one month. Some children may have problems for up to three months or longer.

The purpura on the skin disappears – and usually does not leave any scars – and the joint pains and tummy pains go away. For children with HSP nephritis (where the kidneys are involved), your doctor will check for continued protein and/or blood in their urine.

Relapse

In a few children, the symptoms and signs come back, usually within one year. This is called a **relapse**. These children may need to go back to the hospital, and may need further treatment.

Follow up

All children who have been treated for HSP affecting their kidneys will have follow-up appointments throughout their childhood. 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 **blood pressure** measured.
- a physical examination
- **urine tests** – to check for blood and protein in his or her urine
- **blood tests** – to check for the amount of protein and other substances in his or her blood, and measure his or her kidney function.

Long-term effects

Most children have no long-term effects from HSP. However, your doctor will let you know if your child needs to see a specialist kidney doctor in adulthood.

Chronic kidney disease

In a small number of children with HSP (fewer than five in 100), the kidneys stop working as well as they should – this usually happens slowly, often over many years. This is called **chronic kidney disease (CKD)**. These children may need further care. They will need to go back to the hospital or clinic for regular follow-up appointments.

If your child has CKD, you will learn more over time about how to help manage the condition, and what to expect.

Impact on your child and family

Children who have HSP can usually do the things that other children their age do. They should be able to continue going to school or nursery. They can play with other children and, once they have recovered from the initial illness, they can be normally active.

Living healthily

Your child can help protect his or her kidneys by leading a healthy lifestyle throughout 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.

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.**

Further information

This is the end of the information on HSP. If you would like to read more about other kidney conditions, tests and diagnosis, treatment or 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



© BAPN and Kidney Care UK 2013-2022, all rights reserved

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.

The British Association of Paediatric Nephrology (BAPN), Kidney Care UK and the contributors and editors cannot be held responsible for the accuracy of information, omissions of information, or any actions that may be taken as a consequence of reading this information.